DOCUMENT RESUME

ED 335 850 EC 300 592

AUTHOR	Intriligator, Barbara A.; Goldman, Harvey
TITLE	The Part H Initiative: Towards a Community-Based Service Delivery System for Infants and Toddlers with Handicaps and Their Families.
INSTITUTION	Georgetown Univ. Child Development Center, Washington, DC.; ICA, Arlington, VA.
SPONS AGENCY	Health Resources and Services Administration (DHHS/PHS), Rockville, MD. Bureau of Maternal and Child Health and Resources Development.
PUB DATE	Feb 89
NOTE	159p.; For a related document, see EC 300 591. Small, filled type in figures 1 and 2 may affect legibility.
PUB TYPE	Reports - Research/Technical (143) -- Reports - Evaluative/Feasibility (142)
EDRS PRICE	MF01/PC07 Plus Postage.
DESCRIPTORS	Accessibility (for Disabled); *Agency Cooperation; At Risk Persons; Case Studies; *Community Programs; Cooperative Planning; Coordination; *Delivery Systems; *Disabilities; Early Intervention; Educational Legislation; Federal Legislation; Infants; Information Needs; *Local Government; Parent Attitudes; Preschool Education; Program Development; Staff Role; *State Government; Technical Assistance; Toddlers
IDENTIFIERS	*Education of the Handicapped Act 1986 (Part H)

ABSTRACT

This report examines issues that need to be addressed to create a comprehensive community-based early intervention system, in conjunction with provisions of Part H of Public Law 99-457. The report examines issues addressed by service providers in local jurisdictions developing programs for infants and toddlers with handicaps and their families, and reviews relationships between and among State and local planning initiatives. The research was designed as a case study of a mid-Atlantic State with a variety of demographic characteristics. Data were gathered through interviews with 30 state officials, 30 parents, 9 pediatricians, and 50 personnel from local jurisdictions. Findings are presented as they relate to information and accessibility issues, local planning issues and concerns, and state/local relationships. Recommendations and action steps for developing a community-based Part H service system are outlined. Technical assistance activities suggested by the study findings are discussed. Appendixes contain: (1) an executive summary of "A Profile of State Interagency Efforts for Children with Special Needs and Their Families" (EC 300 591); and (2) a discussion of the features of interagency efforts in terms of cooperation, coordination, and collaboration. (JDD)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)
☑ This document has been reproduced as received from the person or organization originating it.
☐ Minor changes have been made to improve reproduction quality
• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy

ED335850

THE PART H INITIATIVE: TOWARDS A COMMUNITY-BASED SERVICE DELIVERY SYSTEM FOR INFANTS AND TODDLERS WITH HANDICAPS AND THEIR FAMILIES

February 1989

4212 South 32nd Street
Arlington, Virginia 22206

"PERMISSION TO REPRODUCE THIS MATERIAL HAS BEEN GRANTED BY
Barbara Antrilgator
TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)."

EC300592

BEST COPY AVAILABLE

THE PART H INITIATIVE:
TOWARDS A COMMUNITY-BASED SERVICE DELIVERY SYSTEM FOR INFANTS AND TODDLERS WITH HANDICAPS AND THEIR FAMILIES

Prepared by

Barbara A. Intriligator and Harvey Goldman

ICA
4212 South 32nd Street
Arlington, VA 22206
(703) 931-6809

February 1989

This research was sponsored by the Bureau of Maternal and Child Health and Resources Development, U.S. Department of Health and Human Resources and was conducted as a subcontract to the National Center For Networking Community-Based Services, Georgetown University.

TABLE OF CONTENTS

EXECUTIVE SUMMARY i

THE FEDERAL PART H INITIATIVE 2

The Early Intervention Focus. 3
The Family Dimension 4
Interagency Coordination. 6
The Call For Change 9

SEQUENCING PLANNING ACTIVITIES. 10

PURPOSE OF THE STUDY. 13

RESEARCH PROCEDURES 15

Stage 1: A Profile of State Planning Activities 15
Stage 2: Accessibility Issues 16
Stage 3: Local Planning Issues And Activities 17

SITE OF THE STUDY 18

State Programs And Services 19
Local Programs And Services 23
Local Interagency Activities. 25

INFORMATION AND ACCESSIBILITY ISSUES. 27

Views From Parents 28
Characteristics of the Sample 28
Issues Related To Diagnosis 30
Issues Related To Information 33
Issues Related To Accessibility 37
Views From Pediatricians 44
Characteristics of The Sample 44
Issues Related To Information 45
Issues Related To Accessibility 50
Views of Local Service Agency Personnel 53
Characteristics of The Sample 53
Issues Related To Information 54
Issues Related To Accessibility 58
Summary of Information And Accessibility Issues 61
Information Needs 61
Accessibility Needs 64

PLANNING ISSUES AND CONCERNS IN LOCAL JURISDICTIONS 65

Context 65
Creating A Structure For Part H Local Planning. 68
Appointment of A Local Lead Agency. 69
Agency Constraints To Delivering Part H Services 72
Creating A Local Part H Interagency Council 76
Part H Program Issues 80

STATE AND LOCAL RELATIONSHIPS 83

State Part H Planning Activities. 83
State And Local Part H Interactions 89
Communication And Information Sharing With Locals 90
Agency Interactions With Locals 93
Establishing Facilitative State/Local Relationships 95

DEVELOPING A COMMUNITY-BASED PART H SERVICE SYSTEM 100

The Need For Action 101
Recommendations 107
Action Steps. 111

TECHNICAL ASSISTANCE FOR PART H PLANNING 115

The Need For Training 116
Training Activities To Make Collaboration Work. 117
Building Collaborative Part H Structures. 117
Operational Procedures That Support Part H Collaboration. . . 119
Conditions Required For Implementation Of Part H. 120
Summary 121
Training Activities That Facilitate State/Local Coordination. . . . 122
Establishing Structures That Enable Coordination. 122
Operational Procedures That Support Coordination. 124
Conditions Required To Support Coordination 125
The Time Is Now 126

CONCLUSIONS 126

APPENDIX A: Executive Summary: State Profile Of Interagency Efforts . . . 127

APPENDIX B: Features Of Interagency Efforts 132

REFERENCES 146

EXECUTIVE SUMMARY

This report represents the completion of a study of State and local planning for the development of services for infants and toddlers with handicaps and their families. Issues related to State interagency efforts associated with the creation of a service delivery system for these clients are described in an earlier report entitled "A Profile of State Interagency Efforts For Children With Special Needs And Their Families" (ICA, 1988). In brief, it was demonstrated that State level Part H planning requires the establishment of collaborative interagency arrangements among those State service agencies and executive offices involved in the Part H initiative. The focus of this report is on the local community, where Part H services will be delivered. Issues that need to be addressed in order to create a comprehensive community-based early intervention Part H service delivery system were examined.

The Part H Initiative

P.L. 99-457 provides for a five year planning period during which States are developing strategic plans for how best to coordinate and develop Part H services. Early intervention, family support services and the development of collaborative interagency arrangements are the components of the Part H initiative that will require State and local service agencies to conduct some of their business differently --that is, to change the philosophical orientations that drive their services, to add additional atypical services to their current offerings and to work collectively to organize and implement comprehensive early intervention service delivery systems. It is within this climate of change that State and local Part H planning activities will be accomplished.

Intent of The Study

The intent of this study is to identify those planning and policy issues that are most likely to influence a State's capacity to plan and develop comprehensive, community-based service delivery systems for infants and toddlers with handicaps and their families. To provide a focus for the data gathering activities, areas of inquiry included an analysis of State interagency planning activities, an examination of issues that need to be addressed by service providers in local jurisdictions, and a review of the relationships between and among State and local planning initiatives.

Site For The Study

The research was designed as an in-depth case study of a mid-Atlantic State that has 24 local political jurisdictions with a variety of demographic characteristics. They range from densely populated urban jurisdictions to

large and medium sized suburban localities to small sparsely populated rural areas. The State was chosen for this study largely because of its long standing progressive attitudes toward providing services to persons with handicaps and because of the value it places on interagency efforts to deal with issues related to that population. In addition, educational services for infants and toddlers with handicaps have been provided in this State since 1980.

State Part H planning activities have been in progress for eighteen months. A considerable portion of the first year's planning activities focused on State level planning issues required by the legislation. At this point in time, approximately two and a half years since passage of the legislation, no regulations which would provide guidance to State Part H planners have been issued by the U.S. Department of Education. As a result, Part H planners in the State under study report that they have been unable to develop enabling State level legislation and/or to provide more definitive direction to local jurisdictions.

To date, State Part H planning efforts have been both aggressive and comprehensive. Highlights of those State activities designed to foster local involvement include: awarding five grants to counties for the development of model demonstration IFSP processes; sponsoring eight Topical Input Sessions in local jurisdictions across the State; extensive data gathering activities; establishing a network of local service agency contacts; and appointing formal Work Groups to advise the Infants and Toddlers Programs on various dimensions of the Part H service delivery system.

Research Procedures

This in-depth case study was conducted in three stages. In stage one, selected personnel from all of the major State Departments and Executive Offices that are involved both directly and indirectly with planning or programs for children with handicaps and their families were interviewed. Respondents held positions of responsibility for policy, program development and/or coordination of services for this targeted population. Thirty persons were interviewed between November 1987 and April 1988. In addition, participants were involved in verification of the data both through attendance at a meeting scheduled to enlist feedback about the preliminary report and through a series of phone conversations and meetings with persons who were unable to attend.

Data related to the last two stages of the study were gathered between July 1988 and November 1988. First, parents of children with handicaps and pediatricians from across the State were interviewed in order to identify issues that need to be addressed to create an accessible service delivery system. The concerns expressed by each group about information needs and program accessibility were analyzed and recommendations were developed.

Parents and pediatricians who were involved in this study were selected primarily from the six counties that would be involved in the final stage of the study. Nine pediatricians from across the State were interviewed along with thirty parents who had children with a wide range of handicapping conditions. A composite of pediatrician and parent views about information and accessibility was developed and then shared with key personnel in local service agencies in order to ascertain the ways in which local Part H planning initiatives might address these issues.

In-depth studies were conducted in the six participating local jurisdictions. Data were gathered in the following areas: [1] programs and services currently available to infants and toddlers with handicaps and their families; [2] issues that need to be addressed as local planning initiatives are developed; [3] the ways in which State planners are working with local jurisdictions; and [4] strategies that could be used to develop productive working relationships between State and local Part H planners. In each county, individuals from the local service agencies and executive offices involved with children with handicaps and their families were interviewed, as well as private providers and parents. Agency respondents held positions of responsibility for policy, program development and/or coordination of services for this targeted population in their respective counties. A total of 50 persons were involved in stage three data collection activities, 47 agency personnel and 3 representatives of private provider agencies. A preliminary report was produced and all respondents in each of the participating counties were asked to participate in a data verification process to ascertain the extent to which the content of the preliminary report conformed to the kinds of issues and concerns they shared during the interview process.

Findings Related To Information And Accessibility Issues

Given the requirements of Part H, the need to provide information about available services to a broad population is evident. The expressed needs of parents for directories, referral offices, on-line directory services, central resource rooms, and the use of non-traditional means for reaching those who commonly "fall through the cracks" indicate a need for the use of multiple strategies in seeking those who will be eligible for Part H services. Each of these methods for disseminating information and identifying clients is necessary, but no one is sufficient to reach the potential array of Part H clients.

For the most part, the accessibility concerns of parents and pediatricians focused on ease of entry into the service delivery system, speed of assessment procedures, rapidity of service delivery implementation, and service agency capacity to outreach to potential Part H clients. Part H planning initiatives would be immeasurably strengthened if attention is paid to addressing these accessibility and information issues. By and large, while State and local Part H planners understood and acknowledged these identified

needs, they are not being dealt with systematically in current planning activities at the local level.

Findings Related To Local Planning Issues And Concerns

In all six counties in which interviews occurred, none of the personnel had engaged in planning activities that would address such issues as: [1] establishing a structural framework for the delivery of Part H services; [2] developing a decision-making process for allocation of Part H resources; [3] examining independently and collectively the structural and procedural changes necessary for implementing Part H programs; [4] sequencing planning and development activities to ensure a readiness to begin fifth year implementation activities as outlined in the legislation; and [5] engaging in dialogues designed to address organizational issues inherent in beginning to offer early intervention prevention programs.

The majority of respondents indicated that their agencies were not organized to address prevention issues. Service delivery systems with a prevention emphasis require significant amounts of outreach to clients and families, as well as the broad dissemination of information about available services and an organized multi-agency referral system. Participants in this study indicated that current operations in their agencies are not designed to accommodate these prevention concerns. Initiatives adopted by State agencies and local jurisdictions must address these articulated agency constraints to planning and implementing local Part H services. Moreover, Part H planning initiatives must begin with the creation of a county structure that will facilitate the development of appropriate service delivery systems.

At this point in time, there is no formal structure in place for the planning and implementation of Part H services in any of the local jurisdictions under study. Most participants felt that such a structure needs to be put into place as soon as possible. In order to make these decisions, respondents indicated that local planners would need to examine some constraints that they felt were inherent in their agencies' assuming such responsibilities. Even though there was not general consensus as to what the Part H service delivery structure should look like, participants suggested that it must include the appointment of a permanent local lead agency and the development of a formal Part H interagency arrangement in each county.

There was general agreement that Part H will require the involvement of multiple agencies, that to date these agencies have really not engaged in much dialogue about Part H programs, and that different agencies and/or counties are in different stages of readiness to engage in such interagency efforts. Agency representatives indicated that there was a reluctance to become actively involved in the Part H initiative, primarily because of the challenges inherent in the development of an early intervention system and the concern that needed resources would not be forthcoming. Thus, it was

predicted that agencies will engage in "reverse turf" negotiations to protect themselves from being assigned "too many" Part H responsibilities.

Findings Related To State/Local Relationships

In contrast to the State level planning initiatives, Part H planning activities in the counties under study not involved with the IFSP demonstration grants has not begun in earnest. Agency personnel reported that they were awaiting their "marching orders" from the State.

With only one or two exceptions, local service agency personnel who participated in this study indicated that their respective State agency counterparts [i.e., SDE, DHMH and DHR] had not communicated sufficiently with them about the Part H initiative. Similar feelings were expressed about State Part H planners.

At the same time, opinions varied on what would constitute appropriate State guidance to local jurisdictions concerning Part H. About two thirds of the respondents in this study felt that the State should specifically outline Part H activities that local jurisdictions would then follow. Alternatively, one third of the respondents believed that the State should be less directive, and establish broad parameters and guidelines, but allow the counties to do what they need to in order to implement those guidelines.

It was evident that State Part H planners have initiated a number of activities designed to involve local jurisdictions in the Part H planning process and to keep others apprised of progress in the planning effort. It is equally clear that in those counties not involved with the demonstration grants, and in some cases even within involved counties, the State initiatives have not resulted in the desired effect. The reasons for this "gap" are numerous and include such issues as distance to travel to meetings, the need to expand the number of contact persons in the counties, and the priorities of local service agency personnel confronted with solving immediate crises which occur on a day-to-day basis.

The experience of State and local planners indicates that productive State/local working relationships for Part H are not automatic, nor can they be taken for granted because of previous positive interactions. Respondents indicated frustration because they did not know exactly what the State was doing and, by extension, what they should or could be doing as Part H planning continues. This lack of information allowed, or caused local jurisdictions to go into a "holding pattern." Many respondents felt that time was running out; local actions needed to begin immediately in order to meet implementation timelines. It was time, in their judgments, for the State to engage in serious dialogue with local jurisdictions about Part H.

Recommendations

Parents, pediatricians and local service agency personnel made a large number of recommendations about ways to respond to client information needs, to expedite diagnosis and referral processes, to increase pediatrician awareness of the developmental delays in child development, and to foster agency outreach and ease of entry into the service delivery system.

Both segments --the State and local jurisdictions-- have their work cut out for them in implementing the Part H initiative. While it is true that many responsibilities that each segment must fulfil will need to be accomplished independently, many decisions made by one or the other of the segments will seriously influence activities undertaken by the other. Thus, State and local planners must be thought of as partners in a system that allows them to confront some of the challenges of Part H interdependently. In effect, a critical dimension of the Part H planning process is to establish effective working relationships between State and local planners that enable each segment to do its job well. In order to address these concerns about State/local interactions, it is recommended that

> States should appoint regional committees that would serve as vehicles through which systematic communication and information-sharing between State and local Part H planners would be coordinated.

There will be many activities that such committees could pursue, depending on the specific issues that are present in the State. The important thing is to establish such a process as an integral part of the Part H planning initiative, as a means both to prevent and to redress problems associated with relationships betweens State and local jurisdictions involved with implementation of the Part H initiative. Finally, in order to bridge the gap between the work of these regional committees and the activities of the State Interagency Council [ICC] and lead agency, the chairs of all the regional committees in the State should be asked to serve on a newly appointed ICC Subcommittee.

Recommendations for local jurisdictions regarding the implementation of Part H fall into these categories: planning issues, selection of a lead agency, building a coalition to provide support for the lead agency within the Individual Education, Social Services and Health Departments, conflict resolution issues, and resource needs.

> The County Executive should appoint an ad hoc planning committee for the purposes of recommending [1] creation of a policy-making Part H council to oversee Part H efforts, [2] a local lead agency, and [3] the general responsibilities of these units.

BEST COPY AVAILABLE

Criteria for selecting a local lead agency should include [1] the extent to which a given unit is in the position to adequately represent the philosophic orientation underlying Part H and [2] the extent to which a unit is willing to serve as a facilitator for integration and coordination of services by all the local service agencies

In order to provide a forum for discussion and resolution of the major issues related to Part H, the composition of the Part H Council should include representation by all affected parties.

Agency representatives who serve on the Part H Council must also serve as active advocates of the early intervention process within their own agencies.

Agency representatives who serve on the Part H Council must also serve as active advocates of the early intervention process within their own agencies.

A series of specific action steps are provided for counties that have adopted these recommendations to follow in order to create a structure within which Part H planning and implementation can occur.

This research was conducted as an overall examination of the ability and readiness of the State and localities to implement Part H of P.L. 99-457 as of the second year of the planning cycle defined in the legislation. The technical assistance activities suggested by the findings in this study fall into three categories: [1] the development of appropriate structures for dealing with intra-agency and interagency issues associated with Part H; [2] the establishment of processes that would enable these structures to be used effectively; and [3] the creation of those conditions that would enable the desired processes to have their intended outcomes and effects.

Conclusions

There are three overarching conclusions that were derived from this study. First, Part H service delivery systems must be constituted differently if they are to meet the challenges presented by the legislation. Second, it is not clear that the federal government understood the extent to which change would be required by State agencies and local service providers in order to meet these challenges fully. Finally, enhancing State and local planners' capacities to engage in collaborative interagency activities will be the single most important factor in achieving the Part H mission.

THE PART H INITIATIVE:
TOWARDS A COMMUNITY-BASED SERVICE DELIVERY SYSTEM FOR INFANTS AND TODDLERS WITH HANDICAPS AND THEIR FAMILIES

This report represents the completion of an in-depth case study of State and local planning and actions in the development of services and programs for infants and toddlers with handicaps and their families. Issues related to State interagency efforts associated with the creation of a service delivery system for these clients are described in an earlier report entitled "A Profile of State Interagency Efforts For Children With Special Needs And Their Families" (ICA, July 1988). The executive summary of that report is presented in Appendix A. In essence, it was demonstrated that State level Part H planning requires the development of collaborative interagency arrangements between and among those State service agencies and executive offices involved in the Part H initiative. In brief, such collaboration requires a great deal of interdependence and sharing between and among involved agencies and units. A full explanation of the characteristics of collaborative interagency arrangements, as defined in that report, is presented in Appendix B.

The focus of this report is the local community, where Part H services and programs will be delivered. Data were collected from representatives of the various segments that will necessarily be involved in either using or providing these programs: parents, pediatricians, local service agencies and county executive offices and private service providers.

THE FEDERAL PART H INITIATIVE

In 1986, the U.S. Congress enacted Public Law 99-457, "The Education of the Handicapped Act Amendments of 1986." This legislation continues the federal initiative supported by Public Law 94-142. The 1986 legislation provides continuing support to ongoing special education programs and authorizes several new programs, including Part H. Part H is the section of the legislation that requires States to develop comprehensive coordinated service delivery systems that would provide early intervention services to infants and toddlers with handicaps and their families.

Federal programs associated with Public Law 99-457, and its predecessor P.L. 94-142, are administered by the U.S. Department of Education. The legislation authorizes and requires a broad range of "supportive" services not ordinarily thought of as educational services, including physical therapy, occupational therapy, multi-disciplinary assessments, and speech and language clinical services. In effect, State Departments of Education and local school districts have made numerous changes in their special education service delivery systems since the passage of P.L. 94-142. The philosophy underlying these changes was that additional services needed to be provided to children with handicaps to enable them to have a free and appropriate public education and to avail themselves to the extent possible of the full benefits of participation in the public education system. *Children with handicapping conditions were to be made "first class citizens" in the public education system.*

THE EARLY INTERVENTION FOCUS

With the passage of Part H of P.L. 99-457, all States are required to deliver comprehensive coordinated services to infants and toddlers with handicaps and their families. It was felt that by extending such public services to children with handicaps aged 0-2, many disabling conditions that they develop could be treated more appropriately. For many children early intervention will allow them a better chance to become functionally able citizens. Moreover, early intervention might lessen the debilitating effects of some handicapping conditions. The medical and human services professional communities urged such an early intervention in the belief that the earlier a child with handicaps is identified and diagnosed, the more positive the results of an intervention program. Public policy makers affirmed their acceptance of this early intervention treatment philosophy with the addition of Part H to P.L. 99-457.

Few State and local policy makers and/or service providers would disagree with the philosophical underpinnings of Part H; that is, that prevention of serious debilitation from handicapping conditions is the preferred treatment protocol. However, prevention through early intervention services is not the normal mode of operation for government service agencies. By and large, the programs sponsored by public human service agencies are designed to address visible problems and to respond to societal crises or emergency situations. Indeed, decisions to create public service programs are the result of a policy development process in which planners document that the

"problem" to be addressed is wide-spread and consequential. In effect, the philosophy which drives the provision of public human services is one of maintenance rather than prevention: the challenge is to keep the lid on the highly visible problem and to design service delivery systems that assist persons who are affected by the problem.

Federal policy makers have designed Part H as an early intervention preventative service system, and assigned responsibility for Part H implementation to State and local governmental agencies that have service delivery systems in place that are designed primarily to respond to visible and pervasive problems that threaten the safety and well being of the citizenry. The inherent tension between these two legitimate but conflicting orientations makes the designing of Part H service delivery systems particularly challenging to State and local governments.

THE FAMILY DIMENSION

Given the prevention motif that drives Part H, it is reasonable to identify the client population as *both* infants and toddlers with handicaps and their families. The legislation reinforces the need for parents to be viewed as clients and to play active roles in the training and stimulation of their infants and toddlers. The federal mandate requires that parents be involved as equal partners in the determination of the Individual Family Service Plan, and suggests that they participate significantly in the process. Parents are viewed as responsible and equal members of the early intervention team. To enable this active parental role, administrators of Part H service

delivery systems will inevitably need to confront the tensions that have traditionally existed between the parent and professional communities as decisions are made about appropriate interventions for children with handicaps. These conflicts have been addressed successfully in the past, but not without the expenditure of additional time and energy by all involved parties.

The presence of an infant or toddler with handicaps causes special problems for their families. These children often require phenomenal amounts of parental attention, because their handicapping conditions prevent them from doing many ordinary developmental tasks independently. In addition, the search for appropriate medical, therapeutic and educational services for these infants and toddlers is at best time-consuming, and more often an overwhelming challenge to parents. Hence, Part H service delivery systems must be designed to enhance a family's ability to identify and obtain needed services; promoting accessible services and programs is a major focus of the family support component of Part H.

Also, families often need assistance with day care and babysitting services complemented by opportunities to use respite care programs that allow non-handicapped members of the family to rest and to attend to each other as well as to the child with the handicapping condition. Counseling services, assistance with long-term financial planning as well as opportunities to interact with other families who find themselves in similar circumstances are all needed components of the family support dimension of the Part H service

BEST COPY AVAILABLE

delivery system.

The stress of having a child with handicaps in a family manifests itself in all these immediate and long-term needs that must be addressed in the family support component of the Part H service delivery system. However, as indicated above, public services are currently organized to respond directly to the primary problems of the client, and not to the "secondary" needs of the families of those clients. In effect, State and local agencies, in cooperation with private providers, are being asked to develop a set of family support services that do not fall within their traditional purview --further extending the challenge that Part H presents to State and local service agency personnel.

INTERAGENCY COORDINATION

Children with handicaps and their families often have multiple and interacting needs that must be addressed through the provision of a continuum of services. At present, this broad array of services is not offered by a single agency or organization. Rather, parents need to request these services from a number of different agencies and professionals. These agencies tend to have different eligibility requirements and intake systems that require parents to have an extensive understanding of many different bureaucratic procedures and requirements in order to obtain all needed services for their children.

It was to deal with these inter-related problems that P.L. 99-457 included a mandate for the development of State interagency efforts to provide

direction for coordination of services in the Part H Statewide system. It is generally agreed that in order to create a comprehensive early intervention system, an unprecedented degree of interagency planning and actions will be required by both State and local jurisdictions.

State planning activities necessarily occur in conjunction with local jurisdictions, where most services to children with special needs are provided. With relatively few exceptions, infants and toddlers with handicaps and their families contact professional personnel responsible for determining, coordinating and delivering services in local agencies and facilities, such as schools, regional and community health agencies, local social services offices, hospitals, and physicians' offices.

The Part H program is clearly beyond the capacity of any single State agency which is limited by its own mandate and by its ability or inability to influence other agencies. Moreover, accomplishment of this initiative is dependent upon the extent to which local jurisdictions develop the capacity to build integrated community-based service delivery systems. Thus, State agencies have a major responsibility to develop policies and to organize their Part H planning activities in ways that facilitate and enable such collaborative planning at the State level and in local communities.

Interagency efforts can be characterized as cooperative, coordinative or collaborative. Each of these interagency types represents an increasing amount of interdependence on the part of single agency participants. Planners make decisions about which type of interagency arrangement they will use, depending on the specific purpose that the interagency effort is intended to accomplish. In brief, collaboration may not always be the most appropriate

strategy for agencies to adopt; depending on a set of circumstances that are described in detail in Appendix B, successful interagency activities may also be accomplished using either a cooperative or a coordinative approach.

Government agencies are designed to fulfill their mandates independently. Often interagency efforts are accomplished within an environment that constrains collaboration. In its purest form, collaboration occurs when two or more independent agencies agree on some common need which can not be met independently, or through cooperation or coordination. Single agencies recognize the need for such an activity and the services it can provide to the larger community, but are fully aware of their individual agency limitations to accomplish it independently.

Within the framework of governmental agencies, however, the decision to enter into collaborative efforts is even more complex. First, all of the agencies within a governmental administration are always in competition for the same resources; that is, there is a single State budget with a fixed amount and each agency is competing for a larger share of the existing resource pool. In such cases, there is a natural reluctance to advocate creation of a new initiative which will be in competition for the same resources.

Second, within governmental levels, decisions to engage in collaborative efforts are commonly prompted by executive level policies or expressed desires as well as legislative mandates; thus, the intent may be to meet some recognized "common good," but the recognition and impetus to act may be from some agency other than those which are required to implement the collaborative interagency effort. In such cases, the interplay of influence between

governmental levels, as well as between agencies at each given level, serves as a complicating factor. When the impetus to collaborate emerges from some source other than the implementing agencies, commitment to collaborate is often reduced and accompanied by genuine disagreements about the need to collaborate and how best to satisfy the expressed mandate.

In sum, public organizations typically respond to administrative or policy mandates when making decisions about issues that will be addressed through collaborative interagency efforts. Regular agency responsibilities must continue to be met effectively at the same time as interagency planning and actions occur. More often than not, resources to support interagency efforts are delayed and planning activities create a strain on existing agency resources. Given these administrative issues and organizational constraints, collaboration is rare. The special challenge inherent in P.L. 99-457 is that successful implementation requires the use of collaborative interagency efforts in order to develop a comprehensive coordinated service delivery system for infants and toddlers with handicaps and their families. The difficulty of creating collaborative interagency arrangements further extends the challenges that are presented by Part H to State and local service providers.

THE CALL FOR CHANGE

In essence, successful implementation of the Part H initiative must be accomplished in an organizational setting that confronts all of the challenges discussed above. Early intervention, family support services and the development of collaborative interagency arrangements are the components of the Part H initiative that will require State and local service agencies to

conduct some of their business differently --that is, to change the philosophical orientations that drive their services, to add additional atypical services to their current offerings and to work collectively to organize and implement comprehensive early intervention service delivery systems. It is within this climate of change that State and local planning activities will be accomplished.

SEQUENCING THE PLANNING ACTIVITIES

P.L. 99-457 provides for a five year planning period during which States are developing strategic plans for how best to coordinate and develop Part H services. The legislation also stipulates that each State appoint an interagency council and designate a lead agency to oversee planning and development activities. The sequence of planning activities delineated in the legislation is presented below:

> Section 675. [a]FIRST TWO YEARS--In order to be eligible for a grant under section 673 for the first or second year of a State's participation under this part, a State shall include in its application under 678 for that year assurances that funds received under section 673 shall be used to assist the State to plan, develop, and implement the statewide system required by section 676. (Public Law 99-457)

Requirements for the statewide system as stipulated in Section 673 of this legislation include: [1] a definition of "developmentally delayed"; [2] timetables for assuring that services will be available to all infants and toddlers with handicaps before the beginning of the fifth year of the grant; [3] a timely, comprehensive, multi-disciplinary assessment of each child and his/her family; [4] an Individual Family Service Plan for each child,

including case management; [5] a comprehensive child find system, including a referral system and timelines to be followed in the referral process; [6] a public awareness program; [7] a central directory which includes early intervention services, resources and available experts in the State as well as a listing of research and demonstration projects; [8] a Comprehensive System of Personnel Development; [9] a single line of responsibility through a lead agency to the governor; [10] a policy about contracting services; [11] a procedure for timely reimbursement of funds; [12] procedural safeguards for section 680 programs; [13] establishing procedures for ensuring that personnel involved with service delivery are appropriately trained and meet State standards; and [14] a data compilation system that monitors numbers of infants and toddlers and their families served, types of services provided...

The legislation also prescribes activities to be conducted in the third and fourth years of State planning grants:

> [b] THIRD AND FOURTH YEAR--[1]In order to be eligible for a grant under section 673 for the third or fourth year of a State's participation under this part, a State shall include in its application under section 678 for that year information and assurances demonstrating to the satisfaction of the Secretary that--
>
> [A]the State has adopted a policy which incorporates all of the components of the statewide system in accordance with section 676 or obtained a waiver from the Secretary under paragraph [2].
>
> [B]funds shall be used to plan, develop and implement the statewide system required by section 676, and
>
> [C]such statewide system will be in effect no later than the beginning of the fourth year of the State's participation under section 673, except with respect to section 676[b][4], a State need only conduct multi-disciplinary assessments, develop

> individualized family service plans, and make available case management services

The legislation then allows States that have not adopted the required policy to continue to receive planning dollars if the State has made a good faith effort to adopt the policy and has sound reasons for the delay. In these instances States must produce such a policy before the fourth year of assistance, in effect receiving a one-year time extension. Finally, planning for fifth year activities must include:

> [c] FIFTH AND SUCCEEDING YEARS--In order to be eligible for a grant under section 673 for a fifth and any succeeding year of a State's participation under this part, a State shall include in its application under section 678 for that year information and assurances demonstrating to the satisfaction of the Secretary that the State has in effect the statewide system required by section 676 and a description of services to be provided under section 676[b][2]

In the State under study, full implementation of Part H of P.L. 99-457 is scheduled for 1992. In summer 1987, the Governor appointed the Interagency Coordinating Council [ICC] and assigned temporary lead agency responsibility to the Governor's Office For Children And Youth [GOC&Y]. It is the responsibility of the lead agency, with the advice of the ICC, to plan and implement an integrated service delivery system for the targeted population. State agencies and units are engaged in planning activities to address the fourteen stipulated components of the statewide system. Many of these issues are being studied by sub-committees appointed by the ICC.

The State began its second year of planning in October 1988. In an October 25, 1988 Executive Order, the Governor appointed the State Department of Education as permanent lead agency and assigned monitoring status to the

Governor's Sub-cabinet For Children And Youth. It would appear that State Part H planning and actions to date have focused primarily on designing the statewide system required by the legislation. Additional information about year two activities is presented in a later section of this report. It should be noted that the legislation does not address the ways in which State officials should work with local jurisdictions in planning and developing the Part H initiative. In effect, the timing for local involvement as well as the specific nature of that local involvement has been left to the discretion of the States.

The ways in which the State under study will implement Part H is yet to be determined. For the purposes of this analysis the significant points to note are: [1] the law requires "coordination" of and delivery of services to infants and toddlers with handicaps and their families within their communities; [2] this will require integration of services by State and local agencies to a degree that has not previously existed; [3] the State interagency unit (ICC), the separate State service agencies and local service agencies will experience numerous changes as progress toward the objective is achieved; and [4] State planning activities cannot be accomplished successfully in isolation from planning initiatives in local communities.

PURPOSE OF THE STUDY

The intent of this study is to identify those planning and policy issues most likely to influence a State's capacity to plan and develop comprehensive, community-based service delivery systems for infants and toddlers with handicaps and their families. To provide a focus for the data gathering

activities, areas of inquiry included an analysis of State interagency planning activities, an examination of issues that need to be addressed by service providers in local jurisdictions, and a review of the relationships between and among State and local planning initiatives.

The specific research questions addressed are listed below:

1. What is the nature of interagency efforts on behalf of children with handicaps at the State level?

2. To what extent has the Interagency Coordinating Council adopted a collaborative interagency approach in planning for delivery of Part H services to infants and toddlers with handicaps and their families?

3. What do parents, pediatricians and local service providers view as the key issues that need to be addressed in order to insure that accessible Part H service delivery systems be developed in local communities?

4. What planning activities do local service agencies anticipate will be needed in order to develop effective comprehensive community-based service delivery systems for infants and toddlers with handicaps and their families?

5. What roles have local service agencies, or their representatives, played in State Part H planning initiatives?

6. What issues will need to be addressed in order to synchronize Part H planning initiatives at the local level with Part H interagency efforts at the State level?

Issues and information related to research questions #1 and #2 have been synthesized in a previous report entitled "A Profile of State Interagency Efforts For Children With Special Needs and Their Families" [July, 1988]. A summary of the major findings and recommendations of that report is presented in Appendix A. In this document, information that relates to the remaining research questions is presented. It should be noted that research questions #3 - #6 reflect a modification of the original study design. This change was

necessitated because of information gathered during the study of State level activities [See the description of stage 1 of the study below.].

RESEARCH PROCEDURES

This in-depth case study was conducted in three stages. First, information about interagency planning and actions at the State level on behalf of children with handicaps and their families was collected. An analysis of these data was presented in the first report. Next, data were gathered about accessibility issues inherent in providing programs and services to the Part H population. Third, information was gathered about local planning issues and the relationships between and among initiatives.

STAGE 1: A PROFILE OF STATE PLANNING ACTIVITIES

In stage one, selected personnel from all of the major State Departments and Executive Offices that are involved both directly and indirectly with planning or programs for children with handicaps and their families were interviewed. Respondents held positions of responsibility for policy, program development and/or coordination of services for this targeted population. Thirty persons were interviewed between November 1987 and April 1988. In addition, participants were involved in verification of the data both through attendance at a meeting scheduled to enlist feedback about the preliminary report and through a series of phone conversations and meetings with persons who were unable to attend.

Several documents were also reviewed, including: State agency policies and Executive Orders; State and federal legislation; interagency plans; descriptions of interagency programs sponsored by the governmental units;

information and minutes of State interagency committees, subcommittees and task forces; and descriptions and budget analyses of single agency programs for children with handicaps and their families. Where possible, the researchers attended meetings of the Part H Interagency Coordinating Council under study. Information from these documents and meetings was used both to verify data provided by respondents and to develop the first report.

A preliminary State report was developed and all persons who participated in the data collection activities were asked to participate in a verification process to ascertain the extent to which the content of the preliminary report accurately reflected information provided by respondents. Upon completion of the verification process, the final report, entitled "A Profile of State Interagency Efforts For Children With Special Needs and Their Families" [ICA, July 1988], was produced in collaboration with the National Center for Networking Community-Based Services, Georgetown University, and transmitted to the Bureau of Maternal And Child Health And Resources Development, U.S. Department of Health and Human Resources.

STAGE 2: ACCESSIBILITY ISSUES

Data related to the last two stages of the study were gathered between July 1988 and November 1988. First, samples of parents of children with handicaps and pediatricians from across the State were interviewed in order to identify issues that need to be addressed to create an accessible service delivery system. The concerns expressed by each group about information and program accessibility were analyzed and recommendations were developed.

Parents and pediatricians who were involved in this study were selected primarily from the counties that would be involved in the final stage of the

study. Nine pediatricians from across the State were interviewed along with thirty parents who had children with a wide range of handicapping conditions. A more detailed description of these participants is presented later in the report.

A composite of pediatrician and parent views about information and accessibility was developed and then shared with key personnel in local service agencies in order to ascertain the ways in which local Part H planning initiatives might address these issues. Data about information and accessibility were summarized for each of the participant groups and a comparative analysis of their views was developed.

STAGE 3: LOCAL PLANNING ISSUES AND ACTIVITIES

Six local jurisdictions were selected for study, representing the variety of socioeconomic and demographic conditions present in the State under study. One urban, three suburban and two rural counties were included in the sample. All counties have been involved in offering 0-3 educational services to infants and toddlers with handicaps since passage of the State Department of Education's statute in 1980.

In-depth case studies were conducted in each participating county. Data were gathered in the following areas: [1] programs and services currently available to infants and toddlers with handicaps and their families; [2] issues that need to be addressed as local planning initiatives are developed; [3] the ways in which State planners are working with local jurisdictions; and [4] strategies that could be used to develop productive working relationships between State and local Part H planners.

In each county, individuals from the local service agencies and executive offices involved with children with handicaps and their families were interviewed, as well as private providers and parents. Agency respondents held positions of responsibility for policy, program development and/or coordination of services for this targeted population in their respective counties. A total of 50 persons were involved in stage three data collection activities, 47 agency personnel and 3 representatives of private provider agencies.

In addition, available documents and materials were also analyzed as a means of verifying interview data and obtaining background information. A preliminary report was produced and all respondents in each of the participating counties were asked to participate in a data verification process to ascertain the extent to which the content of the preliminary report conformed to the kinds of issues and concerns they shared during the interview process.

Findings from stage 2 and stage 3 are synthesized in this report and recommendations for the planning and development of effective community-based service delivery systems for infants and toddlers with handicaps and their families are presented.

SITE OF THE STUDY

The research was designed as an in-depth case study of a mid-Atlantic State that has 24 local political jurisdictions with a variety of demographic characteristics. They range from densely populated urban jurisdictions to

large and medium sized suburban localities to small sparsely populated rural areas. The State was chosen for this study largely because of its long standing progressive attitudes toward providing services to persons with handicaps and because of the value it places on interagency efforts to deal with issues related to that population. In addition, educational services for infants and toddlers with handicaps have been provided in this State since 1980.

STATE PROGRAMS AND SERVICES

State agency commitment to persons with disabilities has been expressed through the development of a wide range of programs for persons with disabilities and their families by each of the following State agencies and Executive Offices: the State Department of Education [SDE], the Department of Human Resources [DHR], the Department of Health and Mental Hygiene [DHMH], the Juvenile Services Administration [JSA] and the Governor's Office For Children and Youth [GOC&Y].

Without attempting to provide a comprehensive listing of these efforts, the following are noted as examples of such programs:

- o The wide range of programs, sponsored by the State Department of Education, for infants and toddlers with handicaps, school-aged children with handicapping conditions, and persons with disabilities making the transition from school to work. These programs both precede and respond to Federal and State enabling legislation;

- o Examples of programs sponsored by the Department of Health and Mental Hygiene include: The EPSDT (Early and Periodic Screening, Diagnosis and Treatment) program designed to provide comprehensive health care to children eligible for Medical Assistance from birth through age 21; the program that provides community-based services to technology dependent children who would otherwise be placed in institutions; and the Children's Medical Services program that provides identification, prevention and treatment of medical and

developmental problems to children up to age 22 who have special health care needs.

o Programs sponsored by the Juvenile Services Administration for children and adolescents with handicaps include the System for Evaluation and Treatment of Every JSA Youth and the Deinstitutionalization of the Juvenile Offender Program

o Programs administered by the Department of Human Resources, including a network of Family Support Centers (community-based, locally operated drop-in centers focussing on problems of adolescent parenting) and an intensive case management service for families at risk of having a child removed from the home.

o The many services and programs sponsored by the Governor's Office for Children and Youth as a part of its major commitment to at risk children and their families, including administration of planning activities associated with the implementation of P.L. 99-457; and

o The initiation by the Governor's Sub-Cabinet For Children And Youth, with support from the Casey Foundation, of a project in one local jurisdiction to create "a demonstration interagency service delivery system for troubled families." The State Infants and Toddlers Program, with support from the ICC, is providing supporting funds to promote development of the role of case management as described in P.L. 99-457.

These are just a few examples of the many services and programs that the State sponsors through its Departments and Executive Offices that provide direct and indirect services to citizens with disabilities and their families.

The value that the State places on interagency efforts was exemplified by the establishment of at least three formal interagency committees charged with the responsibility of improving the provision of services and programs for children with special needs and their families. In 1982, the State Coordinating Council (SCC) was created by the Governor as an interagency committee responsible for making residential placements for persons with disabilities.

Other interagency committees responsible for issues focusing on children with special needs and their families were created in 1985 and 1987. The Interagency Planning Committee for Children (IPCC), created in 1985 by the Governor, was intended to establish the basis for interagency planning and actions on the spectrum of issues related to children with special needs and their families. Finally, the Interagency Coordinating Council (ICC) was established in 1987 as a part of the State's response to P.L. 99-457 that mandated, among other things, delivery of comprehensive coordinated early intervention services to infants and toddlers with handicaps and their families.

In stage one of the study, activities related to the formation, operation and outcomes of these three major State Interagency Committees (i.e., SCC, IPCC and ICC) were reviewed. Each of these Committees was intended to be a vehicle through which State departments and executive offices might develop interagency approaches to the delivery of services to special needs children and their families. The extent to which each of these Committees functioned as a collaborative interagency effort was examined and implications were identified for provision of services under Part H of P.L. 99-457.

The seriousness of the State's commitment to the development of effective interagency efforts is evidenced in the recent report entitled Serving Children With Special Needs: [State]'s Evolving System (April, 1988), that was developed by the Subcabinet for Children and Youth at the request of the Joint Legislative Budget and Taxation Committee. The report delineates barriers that the State has faced in its interagency efforts; this analysis reflects the leadership's fundamental understandings of many of the issues

related to interagency collaboration. The authors of the report state that: "Logistical, legal, procedural and professional obstacles have historically impeded any attempts to coordinate care between agencies for clients with multiple needs. Some of the most important impediments are discussed below:

> o Historically, each agency has had somewhat different priorities, and resources are limited. Priorities are substantially rooted in the statutes, which govern agency operations and the General Assembly's budget decisions. Judicial mandates also play a key role in setting agency priorities.
>
> o State Agencies, like private practitioners, often cannot assess clearly, accurately, or early enough, the true needs of a child. Many factors affect the problem of assessment...The entire field of children and youth services is struggling to come to terms with the problem of diagnostic and evaluative validity.
>
> o Each Agency operates its own management information system (MIS), often using many different formats and a wide range of codes to categorize services. ...The difficulties of integrated data collection are increased by unsophisticated and outdated MIS.
>
> o Finally, until recently, the State...had not developed a unified strategy to govern resource expenditure and service delivery to Special Needs Children." (p. 12)

In a section that summarizes future direction, the Sub-Cabinet for Children (whose membership included the Chief Executive Officers of SDE, DMH, DHR, GOC&Y and JSA) concluded that:

> Each of the executive agencies entrusted with a separate piece of the larger human problem presented by vulnerable children and families has done its job well. By re-integrating those separate pieces into the complex human situation they must understand and treat, they have joined their commitments and many of their resources in a way that promises to use society's increasingly scarce public resources in a logical cost-effective way.

> ...The approach outlined in this report is a departure from business as usual: the needs of at risk children will for the first time be systematically evaluated from a multi-leveled perspective, and be met with services designed around the child and family, not with a rigid system into which they must fit, or fall through resulting cracks in the bureaucracy... (pp. 28-29)

This report on Serving Children with Special Needs: State's Evolving System was transmitted to the Legislature in June 1988. It reflects a sensitivity to the challenges that confront public providers as they organize service delivery systems for special populations.

LOCAL PROGRAMS AND SERVICES

In 1980, long before the passage of P.L. 99-457, the State Department of Education passed a statute requiring the provision of educational services for children with handicaps between the ages of 0-2. As a result, the following configuration of educational services is available to some extent in each of the counties involved in this study:

- o Parent Infant Programs have been implemented in four of the six counties in which data were collected. Plans are being made to begin similar programs in the two remaining counties in the near future. The primary focus of these programs is on training parents to engage in infant stimulation activities with their children.

- o Child Find Coordinators in school systems have responsibility for identification of children with handicaps, organizing assessment procedures, and referral. Because of the dramatic increase of potential 0-3 clients, two school systems have organized specialized assessment "clinics" for infants and toddlers with handicaps.

- o Services are offered for 0-3 children utilizing one of three models approved by the State Department of Education: home-based, center-based or a combination of the two. The trend seems to be that most counties have either adopted or are moving toward center-based programs.

BEST COPY AVAILABLE

- o IEP assessments are conducted by multi-disciplinary teams, composed primarily of personnel from local Education and Health Departments.

- o Upon completion of the assessment process, an Individual Education Plan [IEP] is developed for each client. County education personnel acknowledge that the Individual Family Service Plan called for in Part H is much more comprehensive than the IEP.

- o IEP services are provided primarily by staff from local Education and Health agencies, with counties providing related services through the Health Department or through the Education Department or by contracting to private providers.

- o Relatively few counties under study offer summer programs for 0-3 clients; in those counties that do provide summer services, programs are organized as enrichment activities rather than as continuations of the IEP services provided during the academic year. In one county, a small summer program for children with handicaps is sponsored by the Department of Parks and Recreation.

Most Education Department participants in this study felt that the passage of this 1980 Education statute positions the State under study to be further along in its planning for implementation of Part H of P.L. 99-457 than those states without 0-3 Education programs.

By and large, county Health and Social Services Departments do not offer services specifically for persons with handicaps and their families. However, there are a number of programs and services available that are appropriate for, and used by some of the client population whose income levels meet agency eligibility requirements. These include:

- o Community health nurses provided by the Health Department work in the schools and make some home visits as a part of some county Parent Infant Programs.

- o County Health Departments sponsor clinics where they do well-child screening. One of the counties now has a specialty health clinic for children with multiple handicaps. Another county has recently decided to eliminate its well-baby clinics. In two counties, well-baby services have been contracted out to private providers.

- o County Health Departments have High Risk Infant Follow-Up Programs and neonatal care units; some potential Part H clients are seen in these settings.

- o All six county Health Departments sponsor Children's Medical Services Programs. These services are offered to persons with handicaps including technology-dependent persons through these programs.

- o County Social Services Departments currently subsidize programs that provide respite care to families with handicapped children. Participants in this study reported that, by and large, these programs do not have adequate resources to serve the targeted population. In one county, respite care is subsidized with additional funds from the County Executive's Office;

- o County Social Services Departments provide monies for day care services for their clients. Children with handicaps up to age 18 are eligible for these services. A small amount of additional money is provided for families with handicapped children. In one county, additional funds for day care services are provided by the County Executive's Office;

- o There are a number of Health Department and Social Services Department programs designed both to reduce teenage pregnancies and to provide assistance to teen age mothers including clients who have substance abuse and addiction problems.

In effect, the presence of a 0-3 Education statute in this State has, in the judgement of the majority of respondents from Education Departments, allowed State and local planners to put into place the skeleton of the service delivery system that is mandated by Part H of P.L. 99-457. In later sections of this report, issues that participants felt must be confronted in order to expand the service delivery system to include the additional services and programs mandated by Part H and to accomodate its prevention-orientation philosophy are addressed.

LOCAL INTERAGENCY ACTIVITIES

At this point in time, most local jurisdictions have interagency committees that represent cooperative or coordinative initiatives between and

among local Health Departments, Boards of Education, County Executive Offices and Departments of Social Services. Examples of local interagency activities in the State include:

- o Each local jurisdiction has a Local Coordinating Council (LCC) that serves as the local equivalent of the State Coordinating Council in making recommendations for residential placements for children with handicaps.

- o The Parent Infant Program Advisory Council in one county has been meeting every six weeks for the past ten years. Membership has recently been expanded to include representatives from the Department of Social Services in addition to personnel from the Health Department, private providers, the Education Department and parents.

- o Some counties have an interagency council for children and youth which falls under the jurisdiction of the County Executive's Office. Representatives from the Education, Health and Social Services Departments sit on these councils. In two counties, these councils have adopted aggressive roles in planning coordinated services for children. Respondents report that the councils in the remaining counties have played a more passive role to date.

- o Two local jurisdictions reported that their interagency committees formed to oversee the transition to work of persons with handicaps are quite effective. Membership on these committees includes representatives from business and industry, private groups working with adults with disabilities as well as from county Education and Social Services Departments.

- o Two of the local jurisdictions under study that received a grant from the State to develop model IFSP programs have established an interagency committee to oversee these activities. The remaining grant recipient under study expanded a long-standing PIP interagency committee. Membership on these committees includes representatives from Education, Health and Social Services Departments, and in some instances private providers and parents of infants and toddlers with handicaps. Participants affirmed the need to plan these services collectively and to involve all agencies who might later be responsible for delivering Part H services.

- o One county has established a Department of Family Resources within the local governmental structure as well as a Commission on Children and Youth. The Commission serves as a needs sensor for the legislative and executive branches, identifying gaps in

services and establishing interagency committees to study these problems and make recommendations to deal with them. The Department of Family Resources is responsible for coordination of services in the county and works with public and private agencies on these county priorities for children and families. Many respondents felt this would be the ideal location for Part H planning initiatives in their county.

In effect, there are a number of single programs and services offered by Health, Education and Social Services Departments in local jurisdictions in this State, as well as a variety of experiences with interagency efforts at the local level, all of which provide planners with a substantial base upon which to develop comprehensive community-based Part H service delivery systems.

INFORMATION AND ACCESSIBILITY ISSUES

This section of the report includes a presentation and discussion of issues which influence the ability of families with special needs children [1] to learn about services available to them and then [2] to access the service delivery system. The perspectives of parents, pediatricians, and personnel from local Health, Education, and Social Services Departments were elicited and are summarized here.

Accessibility is a multi-faceted concept. When broken down into relevant parts, level of accessibility can be determined by: [a] the extent to which all eligible clients are identified by service providers; [b] the extent to which families of clients are made aware of the services available to them; [c] the degree to which diagnostic and intake systems of State and local service units facilitate obtaining appropriate services; [d] the extent to which the Individual Family Service Plan (IFSP) reflects a true multi-disciplinary effort to address the concerns of clients and their families; [e]

the extent to which approval for State or federal assistance is timely and consistent between agencies; and [f] the adequacy of monitoring and follow-up activities to insure the appropriateness and effectiveness of the IFSP. In particular, data gathered for this study pertained to issues [a], [b] and [c].

Recommendations that emerged from data collected through interviews with parents, pediatricians and local service agency personnel about accessibility issues are provided below. For each sample group, a description of [1] the persons involved in the study; [2] the kinds of information required by those persons and methods for disseminating that information; and [3] issues that need to be addressed in order to insure that potential clients can access the service delivery system as easily as possible. Data from each of the sample groups are compared and a summary of central information and accessibility issues is provided.

VIEWS FROM PARENTS

Characteristics of the Sample

Thirty parents were interviewed during five meetings held in locations which corresponded to some of the local jurisdictions in which Education, Health, and Social Services personnel were interviewed. Three of the groups were brought together by their respective school systems, one was convened through the local ARC, and one through a private provider agency. Three of the groups were ongoing parent support groups and the other two were groups of parents brought together specifically for the occasion. All were volunteers and were told that someone who is conducting a study about the new legislation for infants and toddlers with handicaps and their families would like to talk with them.

In every case, the parents' children with handicaps were between the ages of one and ten. A listing of the handicapping problems experienced by the children of these parents is provided below:

#	PROBLEM
2	Severe medical problems [hole in lung, frequent arrest, closed skull]
2	Heart Defects
1	Born without Thyroid
1	Leukodystrophy
4	Speech and Language Problems
4	Down's Syndrome
3	Cerebral Palsy
1	Cleft Lip and Palate
2	Legally Blind
2	Emotionally Disturbed
1	Colostomy
2	Mild Retardation
4	Autistic
1	Legally Blind and Cerebral Palsy

Many of these children were multiply involved, with problems in addition to the conditions listed above.

All of the handicapped children of these parents were receiving services from their local school systems as a part of the 0-3 Education Program. Seven were receiving additional family support services from the private, non-profit agency that organized their parent support group. One child received training in sign language in the local community from the [State] School for the Deaf. Seven had or were receiving assistance through the respite care program which is State supported. One child was enrolled in a Head Start program.

Parents who participated in this study described their involvement with the existing service delivery system. In nine of the thirty cases, the primary care physician directed the parents to the school system or to Child Find soon after the handicapping conditions were identified. In twenty-one

cases the parent found out about available school system services and programs through friends and neighbors, personal calls and private agencies.

Issues Related To Diagnosis

Eighteen of the thirty parents interviewed reported that diagnoses of their children's handicaps did not occur rapidly enough. For ten of the eighteen cases for which data are available, diagnosis of the handicap did not occur until the ages of six months (one case), one year (two cases), eighteen months (one case), twenty-one months (one case), twenty-two months (one case), two years (one case), twenty-seven months (one case), thirty-six months (one case), and forty-two months (one case). In almost all of these cases, the parents had noticed symptoms of the problems before six months of age, including: refused to breast feed; never crying or making any noise; poor coordination; no eye contact; didn't walk or crawl or talk; and hyperactivity.

While physicians made referrals to other specialists or diagnostic services in many cases, some parents reported that the primary care physician suggested waiting to see if the baby outgrew the problem. Some of those parents who were counseled to wait reported that their physicians treated them as if they were "hysterical" or "overly concerned" or just "not too bright." This problem of late diagnosis was particularly evident in cases of autism, retardation, emotional disturbances and neurological dysfunctions [what the parents refer to as "gray area" children; those who have identifiable problems which do not fall within any established medical syndrome]. It should be noted that half of the pediatricians interviewed for this study also expressed concern about delays in diagnosis and identified a tendency on the part of

some of their colleagues to exercise excessive caution before referring children to specialists for diagnosis of possible handicapping conditions.

If the timing of diagnosis reported by the limited numbers of people involved in this study reflects a trend in the medical community, then a great many children born with or contracting handicapping conditions early in life may never receive Part H services under P.L. 99-457 since they are past two years of age prior to diagnosis. It is possible that primary reliance in the legislation upon a "developmental delay" definition for eligibility for services will mitigate this problem since the symptoms may trigger eligibility whether or not diagnosis is complete; nevertheless, if there is an absence of final diagnosis at an early age, numerous problems are likely to occur with respect to determination of appropriate services.

In addition to early diagnosis, effective Part H service delivery systems will depend upon the point at which clients actually begin to receive services. The length of time defined by local school systems [as a part of the current 0-3 educational program] to identify clients, provide diagnostic services and begin implementation of an Individual Education Plan [IEP] is a full six months.

Figure 1 depicts the timeframe currently being followed by education agencies in implementing P.L. 94-142. It should be noted that under P.L. 99-457. This responsibility will not fall *solely* to education agencies; rather, it will become a multi-agency responsibility.

Figure 1

Timeline for Special Education

Process	Timeline
Screening requested	
Screening completed	30 days (calendar)
Evaluation completed	45 days (calendar)
Eligibility decision	30 days (calendar)
Individualized Education Program (IEP) written	30 days (calendar)
IEP implemented	30 days (school)
IEP reviewed for appropriateness	60 days (school)
Maximum total time:	9 months, 3 weeks

The situation is further exacerbated if the child is born in November of the year, or later, since it is possible that the total process may not be completed until the school year is almost over and the child will have to wait until the following September for services to begin. From our interviews with parents, it appears that there are very few, if any, services available during the summer months and those which are available [in some but not all local jurisdictions] include very few children. Again, while P.L. 99-457 does provide for services while diagnoses are being completed, the nature and

extent of those services must, of necessity, be limited until the diagnosis is completed; thus, full access to services might not occur until the child is almost one year old, should current assessment and diagnostic procedures be followed for Part H clients.

Issues Related to Information

From the parents' point of view, there are two types of information for which they perceive a great need. The first is detailed information about the nature of their children's handicapping conditions and the implications of those disabilities for the children and their families. The second is comprehensive information about the range of services and programs available to them and the eligibility requirements for those programs and services. Respondents indicated that the more information that parents have, the more likely they are to play a meaningful role in this process. In order to facilitate obtaining timely and relevant information about the nature of their children's problems and about services available for children with handicaps and their families, the parents suggested a number of initiatives for consideration and implementation by local service agencies and other Part H planners. Their suggestions are presented and discussed below.

> **A comprehensive directory of local and state services and programs for children with handicaps and their families should be developed. The directory should be in printed form for general distribution to parents and also available as part of the public library on-line information system.**

Parents indicated that upon learning of their children's handicaps, they do not know where to go or what to do. Usually they were referred to the Child Find Program sponsored by local school systems. Once they found out

BEST COPY AVAILABLE

where to go, they reported that the information given them was limited to those services which the local school system makes available. They indicated that these services may not cover the entire range of services that they wished to consider. Parents stated that in order to exercise some control over the nature of their children's treatments, they needed information about all available options to the extent that they exist.

All parents involved in this study indicated that their counties should gather and catalogue information about available services in different kinds of directories. The parents requested that such directories contain information about local and State services for children with different handicapping conditions, including eligibility requirements for services, names and phone numbers of contact persons, and available programs.

They indicated that the availability of this information would reduce the inordinate amount of time parents devote to making appointments with individual agencies only to learn that they and their children are not eligible for the particular services. An associated concern is that, within a single agency [particularly Health and Social Services], there is often a need to make separate appointments with different individuals to find out about specific programs.

Many local service providers involved in this study indicated that there were directories of services available in their jurisdictions. However, parents involved in this study were not able to obtain internal directories of services currently in use by professionals within the agencies. Moreover, parents did not use directories published by county government public information offices or private providers. Most of the parents were not

informed about them. Those who were aware indicated that they did not use the existing directories because information was not specific enough about disability issues.

Some parents requested that counties create on-line directory services through the public library system. These directories should contain the same information found in printed directories; however, it should be updated periodically and be available to citizens seven days a week including non-working hours. A system of this type could be updated frequently and would serve as a supplement to the parent directory referred to earlier.

Parents also expressed a need to have similar comprehensive information about medical services. They recommended that:

> **A directory of pediatricians and other medical providers who are trained to work with children with handicaps should be made available in each local jurisdiction.**

Parents have experienced difficulty finding local physicians who are skilled at working with children who have disabilities. In particular, they are concerned about the lack of physicians who are trained to identify developmental delay. Parents are familiar with the major medical centers that specialize in work with children with handicaps, but need someone locally to work with them. They note that the availability of such doctors is particularly critical in determining the nature of any disabilities as early as possible. A significant number of parent comments also focused on the need for information about dentists and opthamologists who are trained to work with children with handicapping conditions, particularly behavior disorders.

Parents indicated that there is a significant need to obtain information in ways other than through directories. They made two recommendations in this area:

> **A central unit should be established in each local jurisdiction from which parents with children with handicaps can receive comprehensive information.**

Parents expressed the concern that there needs to be some method of obtaining information about services and programs for children with disabilities and their families in one central location. This would eliminate the need for long delays incurred while waiting for information and appointments with personnel from many service agencies and units. This unit would collect information about services available for clients with specific kinds of disabilities as well as about eligibility requirements for the various programs and services. They also recommended that

> **A resource area with information about handicapping conditions be established in the main library in each local jurisdiction.**

Parents have requested that a single area of the main library in each local jurisdiction be designated for information about handicapping conditions. Their concern is that information be available about both the handicaps and the impact on families over time. In a great many cases, parents noted that their long-range family planning [i.e., wills, health plans, consideration of job offers, purchasing of new homes] was likely to be affected by such considerations.

In sum, parents suggested that information be stored and disseminated in these two central locations: a new central county unit and the main library. Some parents expressed the concern that making such information available was

necessary but not sufficient to reach some parents. In addition. they recommended that

> **Non-traditional strategies should be used to make low income and geographically isolated families aware of services and programs available to them.**

A number of the parents interviewed described themselves as being just above the income level at which they would qualify for free health and social services benefits. They were, however, concerned that some families who would qualify for such benefits were not aware of the services or programs for which they were eligible. These families were, they felt, "falling through the cracks." In both the rural and urbanized areas of the State in which the study was undertaken, it was reported that there are numerous families with young children who have handicaps or demonstrate serious developmental delays and who are not aware of services available to them and their children. In many cases these parents may not even be aware that their children have a handicapping condition since no explicit medical problem exists. The parents interviewed felt that, in order to reach these families, it would be necessary to mount an aggressive information campaign using non-traditional strategies for disseminating information, such as working through churches and local recreation centers.

Issues Related to Accessibility

Parents of children with handicaps also expressed concern with the degree to which services for which they are eligible are also accessible. Accessibility refers to the speed with which they and/or their children are able to enter the service delivery system, and those associated issues related to their ability to take advantage of services for which they are eligible.

The recommendations made by parents of children with handicaps to facilitate accessibility to services are described below.

Diagnostic centers that work especially with infants and toddlers with handicaps and their families should be established in each local jurisdiction.

The parents recommended that diagnostic centers for infants and toddlers and their families be established in each local jurisdiction. These centers should be staffed with full-time personnel capable of determining whether or not an identifiable handicap exists. The diagnostic center should have the capability to diagnose educational, health, and family needs of those children and their families. The children and their families could then be referred to those agencies having services for which they are eligible.

Parents also indicated that the diagnoses developed by the diagnostic center should then be accepted by all of the relevant agencies and should replace the need for separate screening, evaluation, and eligibility determinations in each agency or in units within the agencies. Parents recommended that the information needed by all of the local agencies be obtained in these centers, preferably on a single information form, facilitating determinations of eligibility for services from all local and State agencies. It should be noted that several local service agency personnel involved in this study indicated that there might be a problem with confidentiality under such a system. Parents, they felt, would need to be willing to sign release forms that would enable the sharing of such client information.

Once families have obtained appropriate diagnoses, they are required to deal with individual service agencies. Parents reported that they often

encounter difficulties in working with these agencies. Thus, they recommended that

> **An ombudsman should be available in each county to assist in solving problems encountered by parents seeking services for their special needs children.**

Parents strongly recommended the appointment of an individual or unit to serve as an ombudsman or advocate for the handicapped and their families. This individual or unit should be situated in the Executive Office of the locality and serve a function similar to that played by local Consumer Protection Agencies and Offices For The Elderly. They indicated that an agency ombudsman could serve as a mediator, alleviating parental concerns that have often turned into litigation with P.L. 94-142. Moreover, negative feelings over perceived instances of discriminatory behavior or exclusion from services could be thus addressed in a positive manner.

Parents reported that they had some difficulty using agency services. They made the following recommendations which they felt would make it easier to obtain these services. First,

> **Local agencies should extend their hours of service delivery to accommodate working parents.**

It was strongly recommended that all local agencies extend their hours of service delivery for children with handicaps and their families to include a few evenings each week and some weekend hours. From the parent's perspective, the hours during which agency services [i.e., clinics, education programs, parent training, physical therapy, occupational therapy, and speech therapy] are offered are so limited that many parents are unable to both work and obtain services for their children, even though they have a significant

need for the income that such work would provide.

In addition, parents suggested that they have a need for sibling day care services during the time that they bring their children with handicaps to agencies for services and diagnoses. Thus, they requested that

> **Local agencies should provide assistance with sibling day care while parents are with children with handicaps receiving services.**

Some of the parents explained that they missed appointments for service delivery because baby-sitters for their other children did not show up as scheduled, or were not available, or were not affordable. It was strongly recommended that some type of day care be made available for siblings while parents and their children with handicaps are at appointments or receiving services in local agencies.

In addition, parents expressed the need for respite care to be available to families because of the hardships associated with having a family member with handicaps. They recommended that

> **Information be made available to families with children with handicaps about opportunities for respite care in each local jurisdiction.**

One hundred sixty-four hours of home respite care a year are available to parents of children with handicaps through a State-supported program. Of the parents interviewed, approximately one-third were not aware of this service. For those who were aware of the service, the great majority indicated that they had never benefitted from the program because either all available funds at the local level were expended well before the year was over, or because personnel were not available to provide the service. The County Executive in one of the counties under study provided additional

resources for respite care, but personnel acknowledged that they were still insufficient to meet the needs of clients. Parents recommended that some more equitable means of distributing available funds be developed and that, in cases where qualified respite workers were not available, parents of children with handicaps be trained to provide the service for each other.

In addition, parents reported that often families do not receive or use needed services simply because they have no way to get to them. Thus they recommended that

> **When necessary, local service agencies should provide transportation to services for infants and toddlers with handicaps and their parents.**

Parental concern was expressed about the fact that a number of the local jurisdictions in which interviews were held do not have public transportation, thus making it extremely difficult to take advantage of available services. Parents involved in this study expressed appreciation of the fact that most local school systems did provide transportation for both parents and children to insure participation in Parent Infant Training Programs. Particular concern was expressed about access to services provided by Health and Social Services agencies. Parents felt that such services should be made available in all the local jurisdictions when necessary.

The preceding accessibility recommendations would be of assistance to families and children with handicaps who are aware of the availability of services. However, parents involved in this study reported that there were many parents of infants and toddlers with handicaps who are not aware of, or using, the service delivery system. Thus, they recommended that

Agencies should establish aggressive outreach programs in order to insure that all eligible families enter the service delivery system.

Among some of the parents interviewed, there was a perception that a great many families that are eligible for services do not receive them. Respondents identified a number of possible causes of the problem. Some parents do not have information about what services are available. Other parents lack sophistication in negotiating the obstacles to entry into the service delivery system. Many parents lack the tolerance levels required to keep calling until they reach the "right" people. In the case of low income, or indigent families, parents are seeking to avoid the "stigma" of receiving county services or the "label" of identifying their children as handicapped, retarded, or emotionally disturbed.

The establishment of some means of bringing these families into the service delivery system was strongly encouraged by the parents. Some of their suggestions included that local service agencies adopt aggressive information distribution strategies, enhance child find efforts, and provide better information to physicians about referral procedures.

Parents also expressed major concerns about the costs of supporting their children with handicaps and made the following recommendation.

Local service agencies should reexamine their financial eligibility requirements in order to make accommodations for the extra expenses incurred by families with children with handicaps.

A number of the parents interviewed noted that their family income levels fell slightly above the cut-off point for free or reduced-cost services from Health and Social Services agencies, thus largely excluding them from

such benefits as might be provided. This problem did not apply to educational services since State law requires the delivery of free and appropriate services for all persons with handicaps between the ages of 0 and 21. The inequity expressed by many of these parents was that maintenance of a child with handicaps [particularly multiple handicaps] often necessitates excessive costs that are not factored into the determination of income eligibility. For example, one parent expends $65-$70 per month for Pampers for a seven-year-old with Cerebral Palsy. Agency personnel who participated in this study indicated that in some localities consideration is given to these costs resulting in a somewhat flexible scale, while in other counties agency personnel adhere to the "letter of the law." Parents strongly recommend that excessive non-medical costs of maintaining a child with handicaps be considered when determining income eligibility for services in all counties.

Finally, parents indicated that there was often a gap in needed services provided to their children with handicaps because of the academic year calendar used by local school systems. Therefore, they recommended that

> **Local service agencies should recognize the need for summer services for infants and toddlers with handicaps and take steps to provide such services.**

All of the parents interviewed indicated that their children received services from the local school systems. Parents were particularly concerned that almost no services were available to children with handicaps during the summer months, and the few that were available were very limited in terms of scope and number of children served. The major concern expressed by the parents was that some children with handicaps tend to forget what they have learned without frequent reinforcement, and that the summer months constitute

a long period of time with no systematic reinforcement of lessons learned during the academic year.

VIEWS OF PEDIATRICIANS

Characteristics of the Sample

In order to obtain pediatricians' views about information and accessibility issues, nine practicing pediatricians from six different local jurisdictions were interviewed. Of the nine, one works in a research teaching hospital and is a developmental pediatrician, five were in private practice as developmental pediatricians, and three were in general pediatrics practice. The names of the pediatricians interviewed were obtained from a variety of sources: [1] parents of children with handicaps; [2] local service agency personnel; and [3] physician referral services.

Two of the participating pediatricians reported that they had minimal or no involvement with children with handicaps in their practices, three described themselves as having some involvement with these children, and four had extensive involvement with these children. The names of two of the last four were provided by parents of children with handicaps. Many parents reported that they share the names of pediatricians who work with children with handicaps among themselves at the various parent support groups to which they belong.

The majority of the pediatricians involved in this study demonstrated a sensitivity to the wide range of needs that families of children with handicaps must confront. While they supported the intent of Part H legislation to provide family support services to these clients, they were

concerned that inadequate attention to medical issues may result from increased emphasis on providing family support services.

Only two of the pediatricians were familiar with the Part H legislation and, to a lesser extent, with the kinds of planning activities that were being pursued both by the State and the local jurisdictions to implement that legislation. After being provided with some of that information by the researchers, all but two indicated that Part H planning needed to occur in close cooperation with the medical community. The early intervention focus of the legislation, they felt, could not be accomplished without the involvement of hospitals, medical social workers and practicing physicians. *Pediatricians strongly recommended that coordination of Part H services include substantial involvement of hospitals, physicians and public health officials.*

In addition, several articulated a concern about the case management requirement in the legislation. Five of the physicians who were interviewed believed that the requirement to appoint a case manager for each client and his/her family will be a problem. In addition to their belief that the use of a case manager "puts another layer of bureaucracy" between the child and the primary provider, they were concerned about whether persons who fulfilled those responsibilities would have the necessary skills.

Issues Related to Information

The pediatricians interviewed described two types of information needs: [1] those which they felt would improve their ability to serve children with handicaps and their families in the referral process; and [2] those which they described the parents of children with handicaps as needing. They recommended that the following steps be taken to meet information needs that would

facilitate the physicians' ability to refer these children and their families.

Physicians should be provided with an organized compilation of information about available support services for infants and toddlers with handicaps and their families.

In order to provide their patients and their families with appropriate assistance, the pediatricians indicated a desperate need for an organized listing of public and private health, education, and family support services available from the State and in local jurisdictions. This information should include telephone numbers and names of contact persons with whom their offices could make contact. At the present time, they note that such information is available only in bits and pieces, and two indicated that a primary source of information at the present time is the "Yellow Pages."

In addition to obtaining information about existing services and programs, most of the pediatricians involved in this study indicated that there is also a need to provide training and information about developmental pediatrics to pediatricians. Thus, they recommended that

The Academy of Pediatrics should provide opportunities for practicing physicians to gain information about diagnostic techniques associated with detecting developmental delay conditions.

A need for information and training about identification of handicapping and developmental delay conditions was expressed by five of the pediatricians. It should be noted that a number of physicians working in county Health Departments also identified this need.

Respondents indicated that the more obvious handicapping conditions, such as Spina Bifida, were easy to diagnose, but that those conditions which characterized the "gray area" children were difficult to diagnose, prescribe

for, or to determine appropriate referrals. Respondents suggested that pediatricians who completed their training within the past eight to ten years were likely to have more familiarity with these techniques; however, even most of them articulated a need for periodic opportunities to learn about new developments and techniques in this area.

Several respondents indicated that as a result of physician inability to diagnose problems associated with developmental delay with confidence, *there is a tendency on the part of some physicians to wait until the next "regular" visit [usually in six to nine months] before referring the child to specialists for further diagnosis.*

In addition, many of the families with children with handicapping conditions rely on general practitioners for initial family medical needs, diagnoses, and referrals. The pediatricians indicated that there is also a need to reach general practitioners with information about handicapping conditions and developmental delay to facilitate the diagnostic and referral process. It was felt that this would enhance earlier intervention.

Pediatricians requested information about special technology and equipment available for children with handicaps. They recommended that

> **Information should be provided to physicians about special technology and equipment available for infants and toddlers with handicaps.**

Pediatricians who have been involved with children with handicaps in their practice indicated a need for information to be provided to physicians about the special equipment appropriate for children with various types of handicaps, as well as the sources for obtaining this equipment. These items include, but are not limited to, special car seats for children with casts,

adapted furniture for children with special needs, and adapted clothing for children with handicaps.

Three of the pediatricians who participated in this study requested information about strategies to assist parents and families to cope with the special needs and challenges inherent in daily living with infants and toddlers with handicapping conditions.

Pediatricians involved in this study were also asked to identify the kind of information that they feel is needed by parents of children with handicaps. Their recommendations are described below.

> **Each local jurisdiction should provide a central location where parents can go to obtain information about services and should develop a directory of such services for parents.**

Six of the respondents felt that parents of infants and toddlers with handicapping conditions need a central location where they can obtain information about available educational, public health and family support services. They indicated that it was unreasonable to expect parents to figure out for themselves what services are available and how to access them without some assistance from the professional community.

Three physicians felt that parents need to be better informed about the programs and services to which they are legally entitled. Such knowledge could be enhanced if a directory of services and eligibility guidelines were available to both parents and pediatricians. They also need to be more aware of their rights with respect to decision-making about the services received by their children; this includes better information about their options in those cases where they disagree with agency decisions about their children.

Most of the pediatricians who participated in the study indicated that parents also needed information about how to recognize delays or abnormalities in their children's development processes. Therefore, they recommended that

> **Information about the child development process should be made readily available to parents, especially parents of newborns.**

Since parents are the most intense observers of their children and have extensive opportunities to do so repeatedly in a variety of settings, they need to be made aware of the developmental stages through which children progress and the types of behaviors that are most common in each of the developmental stages. At the present time, parents are often not able to identify specific indicators of problems that their children have. Often, they bring their children in with the general impression that "something is wrong," but the doctors are not able to diagnose the specific nature or genesis of a problem within the brief span of time that constitutes an office visit without more specific indicators of the problem.

Physicians suggested a number of strategies for providing such information. They include: [1] the production and dissemination of a pamphlet which describes the developmental stages; [2] sponsorship of parent training classes in this area by local Health agencies, and/or as a part of requirements for high school graduation; and [3] public information seminars [perhaps at local libraries] and articles in newsletters and local newspapers through which pediatricians would provide this information to parents. Two of the pediatricians who participated in this study are involved in such activities; they reported that parents did, in fact, use such information to identify in their children some indicators of possible handicapping conditions

[i.e., being sick earlier and more often than normal, lack of coordination, and problems with language acquisition].

Issues Related to Accessibility

A number of issues about accessibility to services for families with children with handicaps were raised by the pediatricians. Five of those interviewed expressed concern about the quality of services received by families on medical assistance. They recommended that

> **Public policies and practices need to be reexamined to determine whether they support a prevention orientation to provision of services to families on medical assistance.**

A number of pediatricians expressed concern about the nature of the medical assistance program. They identified several practices that indicated to them that support was only minimally available to families on medical assistance for diagnosing developmental delays. They indicated that regular check-ups are not completely subsidized by the medical assistance program and that real costs of providing a thorough medical examination far exceed reimbursement levels. On the other hand, visits to physicians for crises situations are, in their judgements, adequately reimbursed by the medical assistance program.

Families on medical assistance are advised to get routine check-ups for their children at Well Baby Clinics [where they still exist in local jurisdictions]. The pediatricians reported that these clinics often do not include, as part of their regular services, diagnostic procedures for identifying developmental delay. Many pediatricians and Health Department personnel involved in this study indicated that Well Baby Clinics are

overburdened by too few staff and too many clients; therefore, the time necessary for such diagnostic screening is not available at present.

A few pediatricians suggested that local jurisdictions consider enhancing the capacities of Well Baby Clinics. Many clients who are likely to need careful developmental screening for their infants already use these clinics. Therefore, it was recommended that additional resources be provided to this Health Department program in order to add staff trained to do these evaluations and to increase their current capacity to serve in a preventative mode.

The presence of a multiply involved handicapped child in families imposes extraordinary financial hardships on families with incomes just above the medical assistance line. Therefore, physicians recommended that

> **Local jurisdictions should consider providing some medical assistance to families just above minimal income levels who have children with handicaps.**

For families who fall just above the income levels required for free or subsidized services, costs for regular check-ups and developmental screening from their private providers are often beyond their means. Monies devoted to medical expenses in budgets of low income families with children with handicaps necessarily get used to deal with crises situations more often than for prevention of future problems. The unintended consequence of existing policies about eligibility for medical assistance is that the "haves" and the "have nots" are better able to gain access to preventative services than the "almost haves." Several pediatricians who participated in this study felt that this was particularly problematic for such families who have children

with handicaps, because these children's medical conditions are exacerbated by delays in diagnosis of developmental problems.

Several pediatricians recognized problems associated with the geographic distribution of services in the State under study and recommended that

> **State and local Part H planners should recognize the problems inherent in geographic distribution of services for children with handicaps in the State.**

Services for children with handicaps and their families tend to be more available in some parts of the State than others. In general, this distribution is related to density of population and/or wealth. That is, in the local jurisdictions that are predominantly urban and/or suburban, more extensive services are available. For those in the more remote parts of the State, or even of the counties that are predominantly suburban, prohibitively long distances must be traveled to obtain the specialized diagnostic and medical services required by children with handicaps. In some cases, there is no guarantee that families will be referred to the non-local, specialized services or that they will have access to them if referred. In many cases, referral and access to special services depends upon where you live and/or who your pediatrician is.

Some physicians reported that there is variance in the number and quality of services that children with handicaps and their families receive in different local jurisdictions. They recommend that

> **Local service agencies should review the extent to which clients receive needed services; steps should be taken to allocate resources equitably and to fill gaps in available services.**

For many families, the amount of services that a child or family receives depends largely on where you live, the resources available at the local level, and the degree to which parents are able to access the service delivery system. The diagnosed needs of the child are no longer the primary determinant of services that the child receives. Pediatricians, as well as parents, reported that services made available to children by some local agencies tend to conform to local resource allocations rather than to what will enable the children to minimize or overcome particular disabilities. More uniform criteria for type and amount of services at the local levels is needed, as well as consistent interpretation of those guidelines by agency personnel within and between agencies.

In addition to alleviating possible inconsistent allocation of existing resources to families, physicians involved in this study indicated that families needed additional support services not currently available through the public agencies. These include:[1] counseling to enable these families to accept the problems of handicaps; [2] assistance in understanding and coping with the impact of children with handicaps on other family members; [3] assistance with family management; [4] advice on immediate and long-term financial planning; and [5] support which addresses quality of life issues for both the child and the family.

VIEWS OF LOCAL SERVICE AGENCY PERSONNEL

Characteristics of the Sample

A total of forty-seven local service agency personnel from six local jurisdictions were interviewed: 17 in Social Services, 13 in Education, 16 in Health Departments, and 1 County Office official. In general, those in the

Social Services agencies worked in units that dealt with services to families and child day care as well as those in the protective services area. Within Education agencies, directors of special education and student support services, interagency specialists, child find personnel and early childhood specialists comprised the population interviewed. Generally, the personnel interviewed from Health Departments were from units representing mental health, school health services, family health, nursing services, and services to children. The representative of a county executive office who was interviewed was from a unit involved with total county coordination of issues pertaining to children and youth. Only one of the counties under study had such an office.

All interviewees were professionals who expressed a sincere interest in determining their responsibilities under Part H. *With very few exceptions, these personnel from the various service agencies expressed an interest in learning about parent and pediatrician views of accessibility, and in exploring ways in which their respective agencies can address those issues as a part of the Part H planning initiative.*

Issues Related to Information

Local service agency personnel were asked both to react to some of the accessibility issues that were identified by parents and pediatricians and to identify those issues that they felt would need to be addressed about information needs and program accessibility issues. By and large, they identified issues related to the need for additional information on the part of parents and the agencies. The following is a summary of those issues. They recommended that

Public service agencies should be provided with additional resources to enable agency personnel to develop active outreach programs for families with children who may be experiencing developmental delays.

At present, very little outreach is undertaken by the local Health, Education and Social Services agencies to provide information to parents of children with handicaps. The belief was expressed by the majority of local agency personnel involved in this study that almost all children with significant handicaps are identified through existing information channels, but that many mildly delayed children may escape identification. In addition, in one of the local jurisdictions in which interviews were held, there is a problem identifying children with handicaps who are in non-English speaking families or in families where the parents are illegal aliens.

Most personnel who were interviewed agreed that outreach by public agencies is necessary to insure that the client population is identified; however, they do not believe that outreach is feasible for their agencies without a major increase in resources. It was noted that many parents are not aware of the programs and services available to them and that the problem is exacerbated by the fact that many pediatricians are also not aware of available services and programs. This lack of information impacts most severely on those in the lower income categories. Personnel from Health, Education, and Social Services Departments indicated that they already have more clients than they have resources to handle, without undertaking an aggressive outreach program. A number expressed concern that their respective agencies would be inundated with an unmanageable number of clients. This problem would be further exacerbated, in almost all of their judgments, should

the Part H client group be expanded to include environmentally at risk children.

Finally, agency personnel reported that the continuum of services needed by children who have severe handicapping conditions is not available in all parts of the State or in all parts of each of the local jurisdictions. This is particularly true with respect to appropriate hospital facilities, but also affects such areas as supportive services and medical personnel trained to work with those having handicaps. Families who reside in rural and remote areas of the counties under study are at a distinct disadvantage in this respect.

Directories should be available in each local jurisdiction that provide information about specific programs and services available to infants and toddlers with handicaps and their families.

The majority of personnel from local Social Services, Health and Education agencies involved in this study indicated that information about programs and services should be made available for parents seeking assistance for their children with handicapping conditions. Very few objections were voiced about including information about eligibility requirements and contact persons, as requested by parents and pediatricians involved in this study.

However, many thought that such directories were already available. In point of fact, one of the local jurisdictions in which interviews took place has a directory specifically related to educational services available for children with handicaps; it is available to parents of these children upon request. The remaining jurisdictions have directories of all local services and programs for use by professional agency personnel, but not for parents.

None of the existing directories include eligibility data.

In addition to the need to develop systematic information about programs and services for parents of infants and toddlers with handicaps, local service agencies need to engage in broad public relations activities to ensure that such information reaches potential clients. A significant number of these respondents indicated that a major public relations program about available services and programs is needed, and that in some cases, available literature about programs is confusing. Some advertising of public programs and services takes place in the local jurisdictions [i.e., child find, radio advertising, health fairs, and in the library], but the only one of these directly related to children with handicaps and their families is Child Find. In addition, some agency personnel also cited the need to provide more information to pediatricians about available services and programs.

Agency personnel made the following recommendations about issues that needed to be addressed in order that they would have adequate information to conduct Part H programs efficiently.

> **Local service agency personnel need improved communication channels with hospitals and improved client data bases in order to facilitate the development of an early intervention service delivery system.**

Many major handicapping conditions are apparent in the hospital at the time of birth or soon after, but the local agencies are not always apprised of the occurrence. As a result, there are instances where the parents are not made aware of community services available to them and their children as early as is needed.

Respondents from local Health and Social Services agencies indicated that no separate statistics are maintained for children with handicaps and their families in their agencies. As a result, they cannot identify from their total client base the number of families having children with handicaps, or the types of handicaps represented in their clientele.

In addition, they reported that agencies organize their client data bases differently and currently use non-compatible hardware and software programs. Therefore, it is necessary to develop a system for integrating common information bases that would be of assistance to all service agencies. It should be noted that the State Infants And Toddlers Program has developed a system that can accomodate five specific client identifiers and can be accessed through linking software and boards across agencies. These procedures and technologies would enable integration of the diverse data information systems currently in use in the service agencies.

Most respondents agreed that the availability of such a common and compatible data base would enhance their collective ability to provide services to Part H clients.

Issues Related to Accessibility

All agency personnel involved in this study expressed major concerns about their units' capacities to respond to many of the program accessibility issues identified by parents and pediatricians. Their concerns are presented below.

Existing educational programs already impose financial hardships on agency budgets; extensive new resources are required to implement Part H programs.

BEST COPY AVAILABLE

The concern was particularly prevalent among Education personnel and was associated primarily with the cost of related services which included occupational therapy, physical therapy and speech therapy. Respondents indicated that the cost of providing these services, either by hiring additional personnel or by contracting with private providers to implement the State law which requires a free and appropriate education for all children with handicaps from age 0-21, has become excessive. As one person from an Education agency remarked, "there is a reluctance to refer children for related services because parents will then ask the schools to pay for those services." In part to deal with this issue, schools have drawn very rigid definitions of what constitutes an educational service as opposed to a medical service. Concern was also expressed about the fact that the number of special education students is increasing much faster than the number of other students and that this will drain off the resources available to other students.

At present, Education, Social Services and Health Departments have severe shortages of personnel; Part H implementation will require the expansion of agency staffs and extensive retraining of existing personnel.

Personnel in Health and Social Services agencies noted that the magnitude of the potential clientele in their communities [i.e., all the people who might qualify for services but have not entered the system to seek such services] far exceeds the capacity of those agencies to handle that number of clients. Without seeking additional clients, they already have more clients than they can deal with. Respondents in all the agencies perceive a shortage of qualified personnel to work with infants and toddlers with handicaps under present conditions, and predict that this situation will be

exacerbated with the implementation of Part H.

Agency personnel reported that shortages of trained personnel will seriously impair the delivery of Part H services in a timely and effective manner. *One of the most serious potential consequences of these staff needs [and of the availability of resources described earlier] is that delays will be inevitable between identification, evaluation and service implementation.*

A second consequence of this shortage of resources and staff, in the judgement of the majority of respondents in local service agencies, is that it is unlikely that agency hours can be expanded, as requested by parents. Personnel in all of the agencies indicated that this would pose a problem with respect to available personnel and financial resources. In one of the local jurisdictions, the Health Department keeps its clinics open late one evening a week. The Social Services agencies also are open one evening each week. One school system is currently establishing a staff position for afternoons and early evenings so some services and staff will be available in late afternoons and early evenings. All indicate that it would pose substantial problems to be open on weekends or to increase evening hours. In general, agency hours correspond to the same hours that parents must work. As a result, in a number of cases, the mothers interviewed are unable to work since they must be available to transport their children to services and programs during the working day. Another consequence is that, often, only the non-working parent is available to meet with agency personnel, since the other parent is at work and it is too costly to miss work.

SUMMARY OF INFORMATION AND ACCESSIBILITY ISSUES

The information presented in the "Matrix of Information and Accessibility Needs" [refer to Figure 2 on the following page] was synthesized from all the comments presented in this section. In some cases, the "X's" are the result of comments made and embedded within a discussion of other information/accessibility issues; in all cases, the comment selected to represent an "X" was taken out of context only if it specifically related to the concern under consideration.

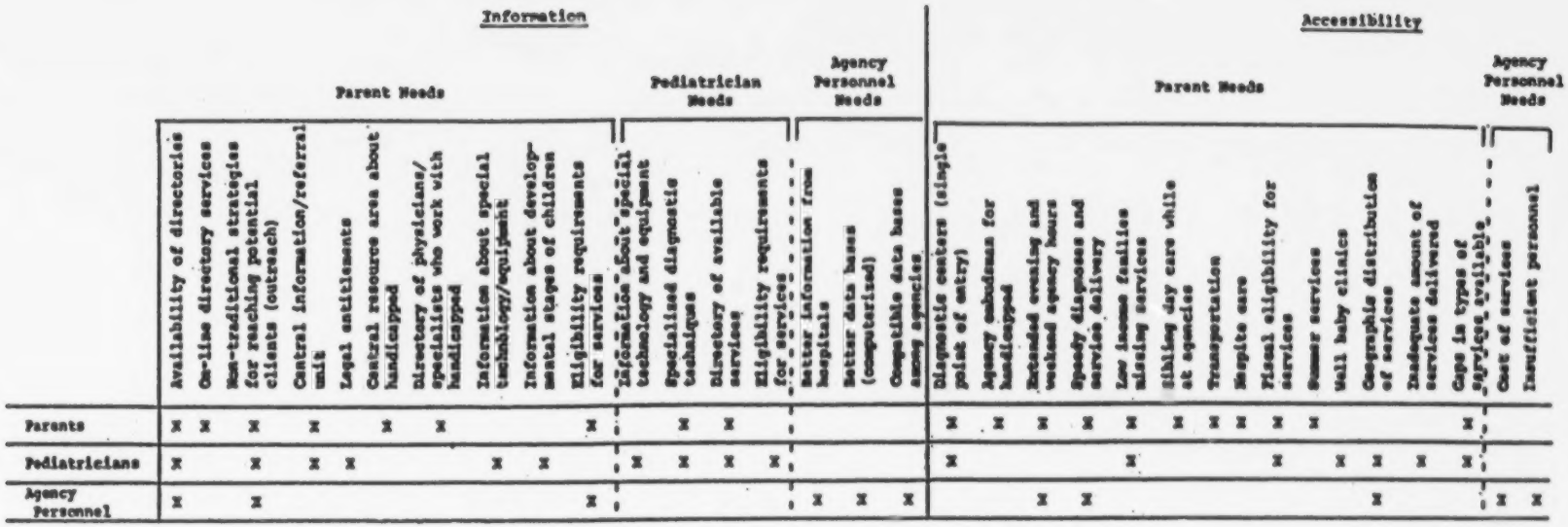
Parents' information and accessibility needs were obtained during the parent group interviews. Pediatricians' perspectives of their own needs and those of parents were obtained during individual interviews held throughout the State. With regard to accessibility issues, pediatricians focused primarily on the needs of parents. Therefore, the accessibility issues section of the matrix does not list a discrete section with pediatricians' needs. In order to obtain the perceptions of service agency personnel, they were shown a partial listing of parents' concerns and asked to respond to the listing. The "X's" on the agency personnel line represent those needs that service agency personnel acknowledged as requiring attention if available resources or personnel permitted.

Information Needs

A review of the information needs listing in the "Matrix" indicates that all those interviewed are seeking additional information that will enable them to carry out their responsibilities more efficiently and effectively. The parents of children with handicaps are seeking information that will permit them to obtain as many of the services needed by their children as possible.

Figure 2

MATRIX OF INFORMATION AND ACCESSIBILITY ISSUES



62

74

75

BEST COPY AVAILABLE

Some pediatricians are in need of information that will enable them to develop better diagnoses of special needs children with greater speed and then to provide accurate information to parents about their next steps in providing services for their children. The service agency personnel feel that better channels of communication need to be established with area hospitals and between agencies -- particularly with regard to their ability to share information about clients whose needs involve multiple agencies.

By and large, the parents interviewed were able to obtain most or all of the services for which they were eligible. As they described it, they had the persistence to keep calling until they found the correct contact persons and the frustration tolerance levels to cope with the bureaucratic systems with which they had to deal. Even in the cases of these parents, however, it was evident to the interviewers that, in a few instances, there were some services for which they were probably eligible and of which they had no knowledge.

This raises significant questions about the ability of other parents with special needs children, those without the needed time, perseverance, and/or frustration tolerance levels, to learn about or to obtain the services for which they and their children are eligible. Both the parents and pediatricians expressed serious concern about the ability of low income parents to learn about or to access the services for which they were probably eligible. While acknowledging this as a significant concern, service agency personnel were also legitimately concerned about the source of monetary and personnel resources that would be required to cope with this potential influx of clients.

Given the requirements of Part H, however, the need to provide information about available services to a broader population is evident. Thus, the expressed needs of parents for directories, referral offices, on-line directory services, central resource rooms, and the use of non-traditional means for reaching those who commonly "fall through the cracks" indicate a need for the use of multiple strategies in seeking those who will be eligible for Part H services. Each of these methods for disseminating information and identifying clients is necessary, but no one is sufficient to reach the potential array of Part H clients.

Accessibility Needs.

For the most part, the accessibility concerns of parents focused on ease of entry into the service delivery system, speed of assessment procedures, and rapidity of service delivery implementation. Those parents, particularly those with special needs children in the 0-2 years old range, were well aware of the high cost of delaying the start of services to remedy the symptoms manifested by their children. Parents who had to wait from six months to two years before final diagnoses of their children's ailments were available and delivery of services could commence were quite bitter about the experience. The provisions in Part H for service delivery to begin if there is an evident need while diagnostic work is undertaken should alleviate this problem.

The second area of concern expressed by parents relates to the type and amounts of services which their children receive. They perceive significant gaps in the services available, and particularly with respect to the needs of families with handicapped children. Among the services needed, but not available, were family counseling, marital counseling, family financial

planning assistance, summer educational experiences, and counseling to meet the needs of children with handicaps. The pediatricians also voiced similar needs for the families of special needs children.

A third area of concern, expressed by both parents and pediatricians, dealt with the amount of services available. This concern was directed primarily at the area of supportive services such as speech therapy, occupational therapy, and physical therapy. Their concern was that, for many of the children with handicaps, provision of these services once and sometimes twice a week (with few, if any, services during the periods schools were closed) was inadequate to effectively remedy the conditions for which they were prescribed.

Part H planning initiatives would be immeasurably strengthened if attention is paid to addressing these accessibility and information issues. By and large, while State and local Part H planners understood and acknowledged these identified needs, they are not being dealt with systematically in current planning activities at the local level. Without a deliberate focus on accessibility concerns in the development process, there is a danger that the resulting Part H service delivery system will be less accessible than what parents, pediatricians, and local service agency personnel believe is necessary. It should be noted that the State under study will propose to address a number of these accessibility recommendations as part of its third year planning activities.

PLANNING ISSUES AND CONCERNS IN LOCAL JURISDICTIONS

CONTEXT

Planning initiatives associated with the Part H initiative are at best a complex process. As indicated earlier, the legislation includes a number of perspectives that are not compatible with existing local service delivery systems. These include the early intervention focus, the family support services orientation and the overarching need for interagency coordination and collaboration. In order to address all of these issues adequately, community-based, prevention-oriented service delivery systems will need to be put in place, which might function separately from the existing service delivery structure. It is through the development of these discrete systems that local service agencies and State units can gain the flexibility to experiment with ways to respond to the three unique dimensions of the Part H initiative.

Findings from data collected from representatives of local Health, Social Services and Education agencies are presented in this section of the report. Participants indicated that in their judgements planning activities in local communities at this point in time await direction from the State. Therefore, information was collected on issues that they perceive will need to be addressed by both local and State planners once local Part H planning begins.

The majority of participants in this study from the six involved counties identified three sets of activities that State planners have engaged in with local jurisdictions: [1] the ICC has held a series of informational meetings around the State for interested parties from the local jurisdictions; [2] five grants have been awarded to different counties to develop model

processes for the Individual Family Service Plan [IFSP]; and [3] Infants And Toddlers Program staff have engaged in data collection activities in county service agencies. The ICC and the Infants And Toddlers Program have been engaged in a number of additional sets of activities designed to set up the statewide system described in the legislation, which are described in a later section of this report. At this point in time, service agency personnel in the counties reported that they are continuing to pursue activities associated with implementation of the State 0-3 Education statute while awaiting guidance from the State about what will be required for Part H service delivery.

An unintended consequence of this delay is that budgets for Fiscal Year '90 have just been submitted by county agency personnel in local jurisdictions. No specific line item requests for development of Part H services and programs were included in these budget requests by Health and Social Services Departments. Moreover, Education personnel reported that in their budget requests, there was a very limited diversion of existing resources to the Part H initiative; rather, funds in local Education Department budgets were designated to provide ongoing support to programs associated with the 0-3 Education program. *Either adjustments in the '90 budgets or requests for supplemental monies will need to be made to insure the availability of resources necessary to support Part H planning.*

In the three local jurisdictions that have received grants to develop a model IFSP process, planning activities center around determining a process for creating an IFSP and for determining the specific content of an IFSP. In the three remaining counties, no deliberate planning for Part H services is

currently underway. Most of the personnel interviewed in these counties indicated that they were awaiting their "marching orders" from the State.

In all six counties in which interviews occurred, none of the personnel had engaged in planning activities that would address such issues as: [1] establishing a structural framework for the delivery of Part H services [including the appointment of a permanent local lead agency]; [2] developing a decision-making process for allocation of Part H resources; [3] examining independently and collectively the structural and procedural changes necessary for implementing Part H programs; [4] sequencing planning and development activities to ensure a readiness to begin fifth year implementation activities as outlined in the legislation; and [5] engaging in dialogues designed to address organizational issues inherent in beginning to offer early intervention prevention programs. These issues are addressed more fully below.

CREATING A STRUCTURE FOR PART H LOCAL PLANNING

At this point in time, there is no formal structure in place for the planning and implementation of Part H services in any of the local jurisdictions under study. Most participants felt that such a structure needs to be put into place as soon as possible. In order to make these decisions, respondents indicated that local planners would need to examine some constraints that they felt were inherent in their agencies' capacities to assume such responsibilities. Even though there was not general consensus as to what the Part H service delivery structure should look like, participants suggested that it must include the appointment of a permanent local lead

agency and the development of a formal Part H interagency arrangement in each county.

Appointment of A Local Lead Agency

Service agency personnel in each county felt that a local agency needed to be assigned responsibility for Part H programs as soon as possible, that the separate Departments needed to know what responsibilities each would have for these Part H initiatives, and that some consideration of how the efforts of separate agencies could be integrated was required.

Selection of permanent lead agencies may be influenced by a recent change in lead agency at the State level. In late October 1988, the State Department of Education [SDE] was appointed the permanent lead agency for the State. As recently as November 1988, many participants in this study were unaware of this change in State lead agency and of any implications this change might have for Part H efforts in local jurisdictions.

Since SDE will administer federal Part H dollars, many participants assumed that those funds will then filter down to local Education Departments making these agencies, by default, the local lead agencies for Part H. However, none of the local education agency respondents in the study indicated that their agencies had been officially designated as permanent county lead agency. In fact, in two of the three local jurisdictions that received grants to develop model IFSP processes, the grants are currently being administered by the local Health Departments. Moreover, many expressed some concerns that will need to be addressed in the event that the decision is made to appoint Education Departments as local lead agencies.

Education staff in all six counties felt confident that the 0-3 educational services currently being offered would serve as a sound framework for the creation of Part H programs. However, most indicated that there would be significant differences in the new programs. These include: [1] an expansion of the kinds of services offered; [2] a much larger pool of eligible clients, particularly when the client population is expanded to include both developmentally delayed infants and toddlers and possibly environmentally "at risk" clients; [3] a critical need for additional personnel as well as for in-service training to assist staff with IFSP planning and implementation; [4] additional resources to support all phases of the program including screening, referral and actual delivery of services; and [5] the development of serious interagency initiatives to support various dimensions of the Part H service delivery system. These education personnel did not identify, as part of these differences, issues related to the provision of family support services compatible with the requirements of Part H.

Participants representing county Health Departments, Departments of Social Services as well as certain county executive offices offered several alternatives to the appointment of local Education agencies as permanent lead agencies. The pervasive feeling was that programs and services required to implement the IFSP required by Part H should be supported by some combination of home-based and center-based programs and that personnel who should provide home-based services should be employees of the Health Department [i.e., community health nurses] or employees of Social Services [family service social workers]. As one Health agency director indicated: "It is a policy question as to which agency will take responsibility for home-based

care...Health does have a visiting nurses referral program, but it is too small to accommodate this new population...our policy now is to let the other agencies do it."

Moreover, many of these personnel felt that school systems had developed a very narrow definition of educational services, which restricts the amount of related services that are included as a part of Individual Education Plan. If that practice continues, then some needed supportive services are not likely to be included in the Part H service delivery system. As one Education Department respondent indicated, "With Education as the local lead agency, we will have an uphill battle...we need to force Education to develop 457 services with the Health Department." A leader in a Department of Social Services summarized this issue: "We need supervision...deciding what agency will be in charge is critical...agencies have different philosophies that will influence direction of services."

Moreover, the majority of Health personnel indicated that Part H infants and toddlers and their families fit more appropriately into the Public Health service cachement area than into Education. As one respondent indicated. "this program is much more central to Health Department needs than to Education...in Education, this population [infants and toddlers] is still considered very exotic, whereas they are already in Health's client system...in effect, the Part H program's mission fits the Health Department, not Education." In addition, several county Health Departments have Infant Assessment Centers which many Health agency personnel believed could be expanded to become the focal point for Part H services. These viewpoints were held by local Health Department leaders in four of the counties under study,

as well as by several of the pediatricians and by five representatives of local Departments of Social Services and Education.

Several respondents indicated that responsibility for planning and implementing local Part H services should rest with a "more neutral county agency...an agency that would serve as an advocate for broader family needs." One Education staff member indicated: "I would love the Part H program to be in the County Executive's Office...in that way, it would have the interagency focus that it needs so badly." This view was echoed by personnel in that county's Health and Social Services Departments, who also felt that agency territorial issues, as well as present heavy demands for services on the three service agencies made the County Executive's Office For Children And Youth the most appropriate choice as local Part H lead agency.

Regardless of which agency is appointed permanent local lead agency in each county, all participants agreed that there was a need to make this decision as soon as possible, as all additional local planning activities would be shaped as much by this decision as by whatever guidance ultimately comes from the State.

Agency Constraints To Delivering Part H Services

It should be noted that there was not an overall eagerness by any of the local service agencies to assume responsibility for the new legislation. Part H is viewed as a preventative early intervention program. The majority of respondents indicated that their agencies were not organized to address prevention issues. As one official indicated, "agencies provide direct services...they are not geared up for, nor do they want to deal with prevention." More generally, a Social Services Director observed: "The issue

is early intervention...but who has ever provided funding to prevent healthy babies from being in danger."

Service delivery systems with a prevention emphasis require significant amounts of outreach to clients and families, as well as the broad dissemination of information about available services and an organized multi-agency referral system. Most participants in this study indicated that current operations in their agencies are not designed to accommodate these prevention concerns. An Education staff member in one county reinforced this position and indicated that "We [Parent Infant Program] have been successful despite the system...we really behave as a kind of private, non-profit agency...the central office lets us...they don't know how the program operates, but they are pleased with it because there have been no hearings since 1980."

Moreover, respondents indicated that "Just standing where we are, we [Health Department] have more business than we can deal with." One county Health Department currently serves about twenty percent of the families in the county that need those services. Education personnel cite major increases in the numbers of children currently being served in the 0-3 Education program. The situation is described as "overwhelming...the school age population is declining in our county, but special education is increasing...it will drain all our resources, not to mention what it will do to our whole system." In another county, there has been a 300% increase in infant and preschool referrals in the last three years [under the 0-3 Education Program], and a third county reported a doubling of referrals in the past year. *Without exception, Education, Health and Social Services agencies in each of the counties*

under study reported that their current resources were being used maximally and in some instances were inadequate to serve their current client population.

This concern about the impact of large numbers of new clients on present service delivery systems is exacerbated when one considers the nature of the potential client population targeted by P.L. 99-457. Eligible clients may include both developmentally delayed infants and toddlers and "at risk" children and their families. The final definition of the "at risk" population in this State has not been articulated; however, most agency personnel expressed concern that expansion to "at risk" families and children would open a "bottomless pit." A Social Services agency respondent indicated that "DSS is actively involved with another at risk group...if you think about the number of potential kids [at risk], you're talking about all the money there is...where is that money going to come from?" A large number of representatives of local Education and Health Departments felt that responsibility for environmentally at risk kids should be assigned to Social Services Departments, despite the "welfare" stigma attached to such agencies. However, as one Social Services leader pointed out, "this [DSS] is a generalist agency in terms of at risk...children with developmental delays are less at risk than children whose lives are at risk...our function is to provide emergency, protective services in the community."

As indicated before, local Departments of Social Services and Health by and large do not offer programs specifically for the handicapped. Respondents felt that existing systems could be expanded to accommodate such programs, if necessary. The more prevalent attitude, however, is illustrated by the following participant comments: "I would prefer not to see our agency [Social

Services] heavily involved with Part H...we get too much that no one gives us adequate resources for now" and "I hope we are not too involved with Part H programs...we [Health Department] are barely able to provide all needed services to our [present] constituencies." Such comments suggest that local agency personnel are aware of the additional burdens that assuming responsibility for local Part H programs would place upon them. *By extension these agencies are for the most part reluctant to assume that additional responsibility without a major infusion of new resources.*

The majority of Education Department personnel in the counties under study also articulated a major concern about the need for additional resources to support the planning and delivery of Part H services. For some, all the State needed to do was to provide additional resources because "we know what to do if a child is born developmentally delayed...why do agencies become defensive...give us the needed resources and we'll take care of it."

Part of this concern emanates from the funding patterns of P.L. 94-142 where federal appropriations only reached a small percentage of promised allocations. Findings from several studies of special education finance issues indicate that *local school systems* have actually been reimbursed for only five to nine percent of excess costs necessitated by P.L. 94-142 even though the initial federal intent was to reimburse at the forty percent level In addition, there was a recognition of the fact that in all of the counties there is enormous competition for human services resources both within and between service agencies. Considering the fiscal implications within a single agency, one Education respondent indicated, "Part H people need to understand the big picture; more mandated special education programs could mean the death

of all frills for other students...there are real social justice issues to examine."

In addition to a general concern about how resources will be provided for Part H services, participants in this study from all three types of service agencies indicated that there will be a serious shortage of appropriate personnel to work with these clients. Health Department respondents felt that community health nurses should play a key role in the home-based component of the service delivery system; yet they all stressed that current personnel levels were inadequate and that many Health staff persons would need additional training before they were able to work with the infants and toddlers with handicaps and their families in this program. Child Find Coordinators in local Education Departments indicated that they were seriously understaffed to accommodate the assessment and referral responsibilities associated with Part H clients as quickly as is required in an early intervention service delivery system. Local Education leaders also indicated that there was a need to provide in-service training to their staff prior to implementation of Part H. All of these concerns about staff capacity and adequacy derive from a growing recognition by most respondents that the development and implementation of an Individual Family Service Plan is dramatically different from, and more extensive than what was required in implementing the Individual Education Plan which is used in the current 0-3 Education program.

Initiatives adopted by State agencies and local jurisdictions must address these articulated agency constraints to planning and implementing local Part H services. Moreover, Part H planning initiatives must begin with the creation of a county structure that will facilitate the development of appropriate service delivery systems.

Creating A Local Part H Interagency Council

In addition to the appointment of a local lead agency, participants in this study felt that local coordinating councils must be appointed to address the multitude of interagency issues associated with Part H. There was general agreement among respondents from Health, Social Services and Education Departments that [1] Part H services would require the involvement of multiple agencies, [2] that to date these agencies have really not engaged in much dialogue about Part H programs, and [3] that different agencies and/or counties are in different stages of readiness to engage in such interagency efforts.

As indicated in the previous description of the "Site Of The Study," there have been numerous interagency committees established in each of the local jurisdictions under study in this State. By and large, participants in the different counties report varying degrees of satisfaction with these interagency committees and planning initiatives, as well as differing states of readiness for engaging in interagency planning for delivery of Part H services. Nevertheless, it is clear that in some of the counties, agencies have a commitment to explore ways to provide county human services

collectively. As one respondent from a Department of Social Services suggested: "Children belong to everybody...if a child turns out to be handicapped, our ability to serve that child is impaired with the existing service delivery system...children need multiple agency involvement to improve their overall quality of life...I don't see this State or the country moving toward this kind of child care."

Respondents provided considerable information about the readiness of their respective counties to engage in interagency activities associated with Part H planning. The general consensus was that "coordination on real issues related to Part H is not being done..." at this point in time. In two of the counties that received State grants to develop model IFSPs, coordinating councils have been appointed for the grants. In the third such county, the existing ten-year old PIP interagency council has been expanded. As one Education Department respondent indicated, in most instances "we are just figuring out the process...what roles each agency will be playing." However, respondents from one of those three sites were very skeptical about whether such initiatives were either necessary or possible, citing negative attitudes by agency leaders and unsuccessful previous efforts with service coordination activities.

A few local jurisdictions have a design and/or process in place which participants feel could be adapted and/or expanded to support coordination of Part H services. Respondents in several counties agreed with one local Education leader who reported that "we work with other agencies close enough

that we already have an interagency design in place...we already have a good relationship with Health and we don't know to what extent we will need to be involved with Social Services around Part H..." In addition, participants from Health and Social Services Departments in four of the counties indicated that their Chief Executive Officers placed a high value on interagency coordination. For example, one Health Department staff person indicated that "the public health officer has a high priority that we use an interagency approach" and a Social Services Department member from another county reported that "there were many interagency committees...because we are such a small county, everybody is involved in everything."

Local Part H planners will need to build on these positive attitudes as they coordinate Part H services and planning activities in their respective jurisdictions.

As a result of their own personal experiences with local interagency committees, the majority of respondents indicated that Part H interagency coordination was likely to be a difficult process. Many echoed sentiments similar to the following observations by a county Health Department leader:

> We need to provide training for interagency efforts ...to learn how to identify key people...territorial issues are also important; we need to understand that it requires juggling your own agency's priorities with priorities of the larger population...each agency must place a high priority on the interagency effort ...synergism is the key concept...

Health and Education personnel from another county reinforced this need: "In this county there are always barriers to doing interagency coordination.

Governmental agencies are not necessarily open to interagency initiatives; some agency people are afraid that the group would want a say in our [ongoing] business."

Ironically, participants felt that territorial issues surrounding Part H interagency coordination might take a different form than what they usually encounter. *That is, agencies would maneuver to make Part H services the responsibility of other agencies, rather than manipulate other agencies to assign them additional responsibilities and resources.* A Social Services staff person indicated that "the issue will be reverse turf...people will want you to take more responsibility than you are prepared to do." The theme which permeates this observation appeared consistently throughout the collection of data about local Part H planning activities: the prospect of being responsible for Part H services is alarming to agency personnel from Education, Health and Social Services Departments in the counties under study. Little confidence is displayed about the willingness of federal, State and local units to provide adequate resources to support those services. Minimal direction has been provided to local service providers by the State service agencies. Given these conditions, agency personnel expressed serious reservations about State and county capacity to fully implement Part H service delivery systems in the State under study.

PART H PROGRAM ISSUES

Respondents from the three local service agencies had varying degrees of understanding about the Part H legislation and about the specific features of

Part H that are different from the State 0-3 Education Program. It should be noted that in general, there was very little information provided to local service agency personnel about Part H. The researchers often found themselves in the position of introducing agency personnel to expectations of the legislation, particularly in terms of kinds of services that would need to be available in the counties. It was clear that the organization and mode of delivery of those services would necessarily vary from county to county. Across the local jurisdictions, most Education personnel and all School Health personnel indicated that they had acquired varying degrees of knowledge about Part H. With very few exceptions, pediatricians and personnel from Social Services Departments and some Health Departments had received little or no information about the Part H program and about their potential roles in the future Part H service delivery system.

Without exception, participants in this study from Education, Health and Social Services Departments, as well as pediatricians and parents, wanted up-to-date and detailed information about State and local Part H planning activities from this point in time.

Given this perceived relative lack of information and the apparent embryonic state of local Part H planning initiatives, respondents were not asked in-depth questions about features of Part H programs. Nevertheless, some agency personnel indicted that the following features of Part H would need to be examined once Part H planning begins in earnest: Assessment and Referral; Case Management; Family Support Services; the Individual Family

Service Plan; and the "At Risk" Definition that will be adopted by the State. These were the dimensions of Part H services that respondents felt most distinguished the Part H program from the 0-3 State Education Program.

Health Department personnel in five counties emphasized the need for a systematic Part H planning process, agreeing that "the key to creating effective service delivery systems is to start planning very far in advance and to involve all key decision makers from the beginning." Personnel in the three counties with IFSP grants indicated that local Part H planning was just beginning and that "lots of creativity is needed at both State and local levels...local Part H planning must include both the county council and the superintendent of schools...its has to happen at the executive level." In the remaining three counties under study, no formal Part H planning initiatives have been reported.

Representatives from all three service agencies in the six counties indicated that their "...agencies need to participate in whatever is being done...even though they might not do much that is different from what they already do in terms of Part H." Finally, the majority of participants agreed with the following statement of one Education Department leader: "Each county has its own service delivery model that comes from activities associated with P.L. 94-142...Part H is a whole different bailiwick...services will need to be offered differently for these kids and their families."

STATE AND LOCAL RELATIONSHIPS

The ways in which State Part H planners and State service agency personnel organize and conduct their planning activities are a critical dimension of the Part H development process. The creation of a comprehensive early intervention service delivery system for infants and toddlers with handicaps and their families cannot be accomplished by any single agency working in isolation from other human service agencies. Rather, the State Department of Education [SDE] in its capacity as State lead agency, and the ICC, must establish collaborative interagency arrangements between and among those units that will need to be involved in the Part H initiative, including the Department of Health and Mental Hygiene [DHMH], The Department of Human Resources [DHR], the Governor's Office For Children And Youth [GOCAY], the Juvenile Services Administration [JSA] and the Sub-Cabinet For Children And Youth. Key issues that need to be addressed by State planners and agencies in order to plan and develop a collaborative Part H interagency effort have been discussed in an earlier report entitled "A Profile of State Interagency Efforts For Children With Special Needs And Their Families" [ICA, July 1988].

STATE PART H PLANNING ACTIVITIES

At this point it is critical to examine the context within which State Part H planning activities has occurred and the nature of those activities. Interpretation of local Part H planners' concerns should be viewed within this context in order to gain a complete picture of the Part H initiative in the State under study. This information also sets the stage for consideration of

the types of interactions required between State and local planners as Part H activities proceed.

State Part H planning activities have actually been in progress for eighteen months. A considerable portion of the first year's planning activities focused on State-level planning issues required by the legislation.

At this point in time, approximately two and a half years since passage of the legislation, no regulations which would provide guidance to State Part H planners have been issued by the U.S. Department of Education. As a result, Part H planners in the State under study report that they have been unable to develop enabling State-level legislation and/or to provide more definitive direction to local jurisdictions.

In addition, the legislative requirements for the first two years of the Part H planning process emphasize State-level organizing and planning activities which must be accomplished to meet the requirements for funding in subsequent years of the five year planning process.

Part H planners in the State under study also felt that it would not be feasible to design a single system for implementing Part H which would be suitable for use in all local jurisdictions within the State. There is considerable variance among local jurisdictions in terms of size, wealth, rate of population growth, and current availability of appropriate services for infants and toddlers with handicaps and their families. Some counties are rural in nature, while others are suburban or highly urbanized.

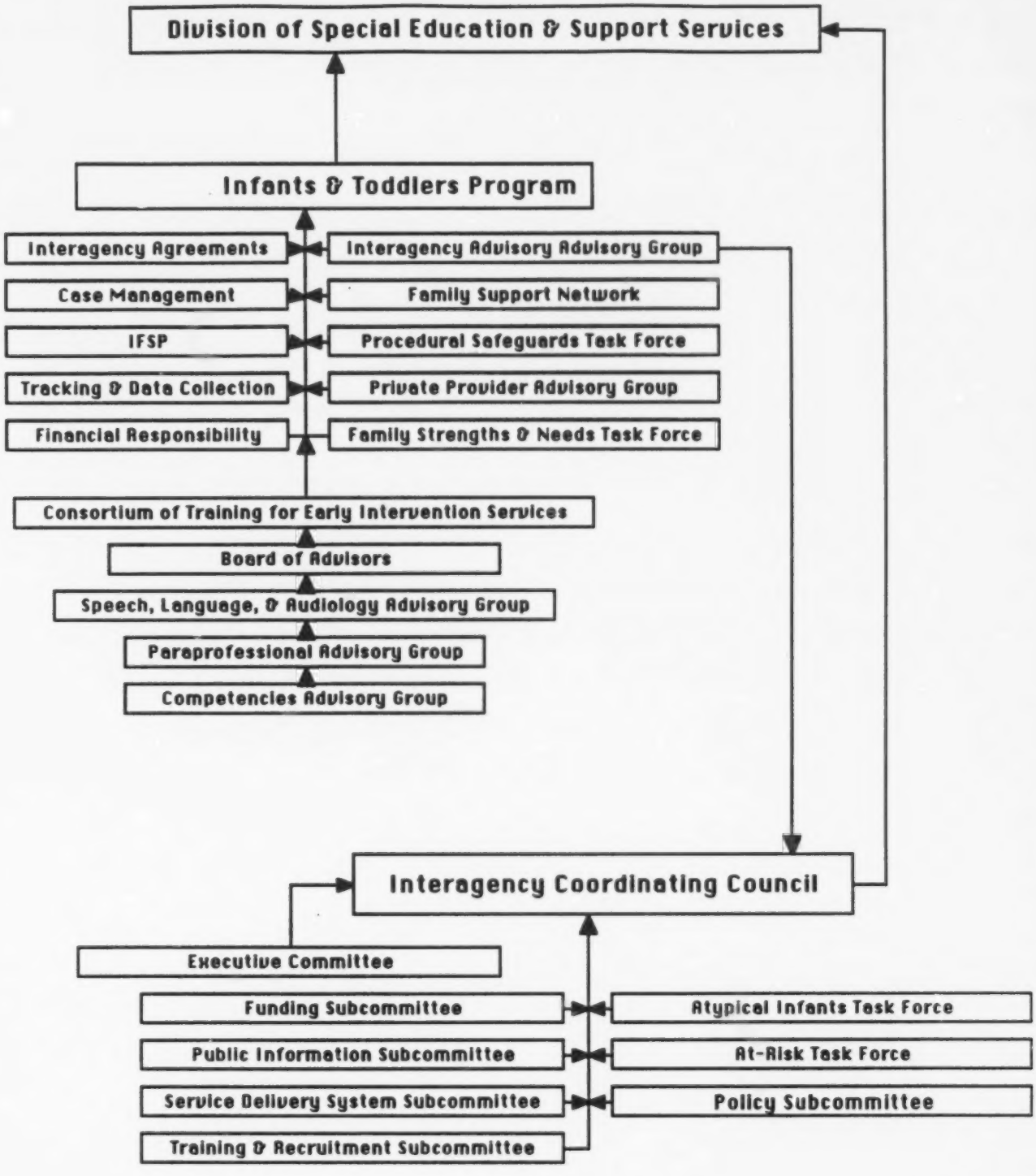
The point made by State Part H planners was that no single early intervention system for Part H clients will satisfy the needs of local jurisdictions with such varied circumstances and needs. Therefore, their expectation is that local Part H planners will have numerous idiosyncratic decisions to make relative to the design of their Part H service delivery systems. Furthermore, State-level guidelines and regulations should, in their judgement, provide a framework within which those decisions will be made rather than specific prescriptions to be followed by all local jurisdictions.

The State Infants and Toddlers Program has also been somewhat handicapped by the length of time and uncertainty that surrounded determination of a permanent lead agency. For the first year, the Governor's Office For Children And Youth [GOC&Y], which was viewed by many as a "neutral" unit in the Executive Office structure, served as temporary lead agency. At the beginning of the second planning year, the State Department of Education [SDE] was appointed permanent lead agency by the Governor, but transition from GOC&Y to SDE took approximately five months. Dealing with issues created by this transition consumed some of the time and energy of the Infants And Toddlers Program staff.

Figure 3 below depicts the current organizational framework for State Part H planning activities. The Infants And Toddlers Program and the Interagency Coordinating Council are both housed within the Division of Special Education and Support Services in the State Department of Education. The Interagency Coordinating Council has established a number of subcommittees

Figure 3

ORGANIZATIONAL STRUCTURE FOR STATE PART H PLANNING



and task forces necessitated by the legislative requirements. Committees and advisory groups established by the Infants and Toddlers Program focus primarily on issues that will be relevant to implementation of an early intervention, prevention-oriented service delivery system for Part H clients at the local jurisdictional level.

Highlights of some the Part H activities that have occurred or that are presently happening at the State level are presented below.

- o Beginning in the first year of planning, the ICC, in collaboration with the lead agency, has appointed subcommittees to develop working papers on the major components of the Statewide system that is defined in Section 673 of the legislation, including funding, development of definitions of the client population, data gathering and analysis and personnel training. Many of these position papers are developed, have been exposed to public comment and adopted by the ICC.

- o Five one-year grants have been awarded on a competitive basis to local jurisdictions to test model processes for development of an Individual Family Service Plan.

- o A special grant was made to the county involved in the Casey Foundation activities to support that effort and to provide coordination between that effort and the work of the Infants and Toddlers Program.

- o Between June and December 1988, Topical Input Sessions were conducted by the ICC and Infants And Toddlers Program staff in different localities across the State to discuss various dimensions of the Part H initiative. Issues addressed included implementation at the local level; CSPD; training and recruitment; IFSP; multi-disciplinary evaluation; tracking; procedural safeguards and dispute resolution; and early intervention and personnel standards. Issues papers reflecting the proceedings of these meetings have been developed and disseminated by the Infants and Toddlers Program.

- o Lead agency staff are engaging in a number of data gathering activities with local jurisdictions to ascertain the extent to which local service providers in Health, Education and Social Services Departments currently provide services to infants and

toddlers with handicaps and their families and the nature of those services and programs.

o At the request of the Infants And Toddlers Program, each local jurisdiction has appointed contact persons from local Social Services, Education and Health Departments to facilitate communication between State and local Part H planners.

o The Infants and Toddlers Program has created a formal Interagency Agreements Work Group which is looking at issues that will need to be addressed in local communities in order to coordinate Part H early intervention services.

o The Infants And Toddlers Program has created an IFSP Work Group whose members include the directors of the five grants for development of model demonstration IFSP's. This group meets regularly to share mutual interests and concerns being dealt with in the development of IFSP processes in their respective jurisdictions.

o A major initiative has been launched to involve parents in State planning initiatives. Parents are members of the Interagency Coordinating Council, the lead agency has appointed a parent leader to assist with the family support dimension of the Part H initiative, and a major all-day meeting that focuses on the special needs and concerns of families is being planned for March 1989.

In contrast to the State level planning initiatives described above, Part H planning activities in the counties under study not involved with the RFP demonstration grants have not begun in earnest. Agency personnel reported that they were awaiting their "marching orders" from the State. From the preceding discussion, it is evident that State Part H planners have initiated a number of activities designed to involve local jurisdictions in the Part H planning process and to keep others apprised of progress in the planning effort. It is equally clear that in those counties not involved with the demonstration grants, and in some cases even within involved counties, the

State initiatives have not resulted in the desired effect.

The reasons for this "gap" are numerous and include such issues as distance to travel to meetings, the need to expand the number of contact persons in the counties, and the priorities of local service agency personnel confronted with solving immediate crises which occur on a day-to-day basis. In the following sections of this report, issues related to developing a framework for improving communication and information-sharing between State planners and local jurisdictions are presented. Adoption of this framework would result in avoidance of some of the pitfalls that were encountered in the State under study.

STATE AND LOCAL PART H INTERACTIONS

In this section of the report, perceptions of representatives from local service agencies about the following issues will be addressed: [1] the nature of Part H interactions between State planners and local jurisdictions, [2] the ways in which the ICC, the State lead agency and the State service agencies should be working on Part H planning with local jurisdictions; and [3] the ways in which local jurisdictions should be working on the Part H initiative with State planners and service agencies.

Participants in this study from the six local jurisdictions expressed some concerns about the extent to which State service agencies, the ICC and the lead agency are providing direction or guidance to local service agencies about the Part H initiative. Their concerns included a perceived lack of sufficient information about State Part H planning activities, limited

interactions with State service agency personnel about Part H, and what was viewed as minimal guidance for local Part H planners from the ICC and the lead agency.

Communication And Information Sharing With Locals

Participants in this study from local service agencies felt that communication should be improved between State Part H planners and local Departments of Health, Education and Social Services as well as appropriate County Executive offices. They reported that Part H information that was received from the State came primarily from the following sources: [1] participation on the ICC and its subcommittees; [2] personal requests for information; and [3] attendance at meetings.

Participation On The ICC And Its Subcommittees. Personnel from two of the counties involved in this study were members of the State ICC; they made it their business to provide their colleagues with periodic progress reports during meetings of local committees and units. In addition, five persons from three counties reported that they have served on planning subcommittees of the ICC and informally disseminated information about their involvement with their immediate units.

It was felt that as a general principle, selected personnel from every local jurisdiction in the State should have some participation on the ICC and/or its subcommittees, and that *part of the responsibilities of these involved local personnel should be to disseminate information about their involvement to their local colleagues on a systematic basis.* In addition, a few participants

requested that the ICC/lead agency provide them with lists of local personnel involved in these State planning activities so that they might be contacted both to learn about their involvement and to provide feedback as these activities develop.

Personal Requests. Several persons from Health, Social Services and Education agencies requested that their names be placed on the ICC mailing list and have since been receiving information regularly. They did not report that they formally shared this information with colleagues in their agencies. Many of those who were not on this list indicated that they had not thought of it. Although this was not the case, they expected that the ICC or the lead agency would have automatically put them on that list because of the positions that they held in their respective agencies.

In effect, local agency personnel who felt that they were not receiving adequate printed information from the State about Part H indicated that receiving systematic written information from the ICC or the lead agency would be helpful. However, others who had been receiving such written information emphasized that increased personal contact with State planners would enhance the usefulness of such written communications.

Attendance At Meetings. Many personnel, primarily from local Education and Health Departments, had attended at least one of the regional meetings sponsored by the ICC in which Infants And Toddlers Program staff made presentations about certain Part H program issues and solicited feedback and general information from attendees about concerns relative to Part H.

Most of these personnel indicated that they were pleased that the meetings were scheduled, but disappointed that more comprehensive information about Part H was not presented in each meeting. Several suggested that a one day, or day and a half meeting be held in which local agency staff would be given the total Part H picture, including information about progress with State planning activities and opportunities to provide input about local concerns and issues. No one reported that they had received and/or disseminated copies of the discussion papers, developed by the Infants and Toddlers Program staff, in which the proceedings of each of these meetings were synthesized.

The three local agency staff persons who have responsibility for direction of their county IFSP grants indicated that an IFSP Work Group of project directors had been formally constituted under the auspices of the Infants And Toddlers Program. It meets periodically to share information about the development of their respective model IFSP demonstration activities. No information was obtained about the ways in which project directors shared information gained from these meetings with colleagues in their respective agencies and localities.

Although there are other means through which State Part H planners disseminate information to local jurisdictions, they were not identified by participants in this study. In effect, the majority of respondents from local Health, Social Services and Education Departments reported that they were not adequately informed [1] about the specific components of the Part H

initiative; [2] about specific activities that State Part H planners were engaged in as they define the Statewide early intervention service delivery system; and [3] about what responsibilities they would need to assume at the local level for Part H. *These concerns centered around the amount of information about the Part H initiative that they had received as well as the strategies that State planners and agencies were using to disseminate that information.*

Agency Interactions With Locals

With only one or two exceptions, local service agency personnel who participated in this study indicated that their respective State agency counterparts [i.e., SDE, DHMH and DHR] had not communicated sufficiently with them about the Part H initiative. Health and Social Services agency personnel all agreed that DHMH and DHR were not sharing any information about Part H with them. Education agency personnel indicated that while SDE typically provided them with timely and necessary information, this was not the case with respect to the Part H initiative. One or two felt that this situation might change now that SDE was the State lead agency. This lack of communication from State agencies was becoming increasingly more anxiety-producing as local service agency personnel began to realize [through information sharing by the researchers] that some Part H services would need to be in place beginning in 1991.

Most respondents felt that the ICC and lead agency were working on State planning activities, but without significantly involving all local

jurisdictions in the process. The majority indicated that the ICC and lead agency should assume the responsibility for [1] coordination between and among State service agencies; [2] developing policies about the ways in which Part H resources would be allocated; [3] disseminating to local agencies, through the lead agency, specific information about Part H decisions that were being made by the State; and [4] providing sufficient guidance to counties to enable them to begin local level Part H planning activities. It should be noted that only a few respondents distinguished between the roles of the ICC and the lead agency, referring for the most part to what the "State" should do to assist counties with the Part H initiative.

By and large, these observations related to things that respondents believed State agencies, the ICC and the lead agency ought to be doing as the State provides guidance to local jurisdictions about Part H. With one or two exceptions, respondents reported that such guidance was not being provided by the State at this point in time. As one local Education Department indicated, "...counties expect to get some substance from the ICC...so far it is a waste of people's time...we expected direction from the State and we didn't get it...there are many issues that need decisions."

At the same time, opinions varied on what would constitute appropriate State guidance to local jurisdictions concerning Part H. These differences reflect the traditional tensions that exist between State authority and local control issues. About two thirds of the respondents in this study felt that the State should specifically outline Part H activities that local

jurisdictions would then follow. As one respondent from a local Education Department indicated: "The State needs to make two kinds of decisions...what are the mission and goals for the ICC...and what is their plan for local participation. It is time to pull it all together." Alternatively, one third of the respondents believed that the State should be less directive, and "establish broad parameters and guidelines, but allow the counties to do what they need to in order to implement those guidelines." "They should involve the locals in needs assessment before developing the State Part H model...we have some good ideas and programs that work, which the State should know about." State Part H planners reported that the delay in issuing specific guidelines was partially due to the fact that the federal government has not yet established final regulations for P.L. 99-457.

Regardless of which role they favored for the State to play in the Part H initiative, all respondents felt that the State needed to provide immediate guidance to the counties. Local level planning, in their judgement, could not proceed without this assistance. One Health Department respondent stated the following, which reflects the opinions of several other participants in the study: " Either the State should come up with rules and regulations and counties will do it, or they should let counties go about developing programs...everyone in this county is frustrated by the lack of action."

ESTABLISHING FACILITATIVE STATE/LOCAL RELATIONSHIPS

The creation of effective Part H early intervention service delivery systems is a complex process. Many State planning activities require planners

to focus on issues that can only be addressed at the State level. Policies that define the general parameters of the State Part H initiative must be developed and enacted. Critical decisions about the ways that the State will utilize and distribute resources obtained from the federal government must be made. In addition, decisions need to be made about the sources of State dollars that will be used to augment federal dollars. States must also conduct planning activities that insure their continuing eligibility for federal Part H planning dollars while at the same time organizing planning so that implementation deadlines are met. And the State Interagency Council must continue to define and facilitate collaboration between and among the major agencies and units that are likely to be involved in the Part H program. These are major challenges that understandably occupy the time and energy of State Part H planners because they must be addressed at the State policy level.

However, actual delivery of Part H services will occur in local jurisdictions. At the same time that State planners are dealing with these policy issues, local jurisdictions have a need to examine the ways in which they will organize and deliver Part H services and programs. As is indicated in other sections of this report, implementation of an effective early intervention service delivery system in local jurisdictions is likely to require significant time and energy on the part of local service agency and county executive office personnel. The special concerns that local service providers must address in order to comply with the federal Part H legislative

guidelines must be identified early in the planning process.

In effect, requiring local service agencies to deliver preventative services compels the development of local policies that address issues separate from the previously described State activities. Decisions need to be made about what agencies and/or committees would most appropriately be assigned responsibility for developing and implementing Part H programs and services, and a lead agency assignment must be made. Steps needed in order to facilitate the speedy and effective identification, diagnosis and referral of Part H clients in a prevention-oriented system must be defined. Procedures must be established that will be used to facilitate collaborative interagency relationships among community service providers who will be involved in the Part H service delivery system. These are just a few of the issues that local jurisdictions will need to confront as a part of their community-based Part H planning and actions.

Both segments --the State and local jurisdictions-- have their work cut out for them. While it is true that many responsibilities that each segment must fulfil will need to be accomplished independently, many decisions made by each of the segments will seriously influence activities undertaken by the others. Thus, State and local planners must be thought of as partners in a system that allows them to confront some of the challenges of Part H interdependently. *In effect, a critical dimension of the Part H planning process is to establish effective working relationships between State and local planners that enable each segment to do its job well.*

The overall Part H policy in each State, as called for in the legislation, will be influenced equally by federal requirements, State rules and regulations, and local needs and concerns. Information about each of these three areas must be used to guide the development of that policy. To omit data about any one of them is to develop a policy that is not likely to work.

Indeed, the experiences of State and local planners in the State under study indicate that productive State/local working relationships for Part H are not automatic, nor can they be taken for granted because of previous positive interactions. Respondents indicated frustration because they did not know exactly what the State was doing and, by extension, what they should or could be doing as Part H planning continues. This lack of information allowed, or caused local jurisdictions to go into a "holding pattern." Many respondents felt that time was running out; local actions needed to begin immediately in order to meet implementation timelines. *It was time, in their judgments, for the State to engage in serious dialogue with local jurisdictions about Part H.* In order to address these concerns about State/local interactions, it is recommended that

> **States should appoint regional committees that would serve as vehicles through which systematic communication and information-sharing between State and local Part H planners would be coordinated.**

The State under study should appoint similar committees in each of its geographical regions that would be charged with the responsibility of facilitating productive State/local relationships in the Part H planning

BEST COPY AVAILABLE

process. The primary purpose of these committees would be to promote and facilitate positive working relationships between State and local Part H planners through the improvement of communication channels and the dissemination of timely information. The committees would meet monthly during peak planning periods, and less frequently as implementation proceeds.

In order to accomplish this mission, membership on these committees needs to include representatives from all the major State and local segments involved in the Part H initiative. Therefore, it is recommended that each regional committee have the following members:

- o One decision-maker from each State service unit and executive office involved in the Part H initiative;
- o Three persons in authority from each local jurisdiction in the region: one from the Health Department, one from the Education Department, and one from the Department of Social Services; and
- o One staff member from the State Lead Agency's Infants and Toddlers Program

As a general rule, members should be able to speak with authority about Part H issues of concern in their home organizations

The regional committees might engage in a number of activities designed to address concerns about State/local relationships raised by participants in this study, including

[1] Developing a process for collecting and disseminating up-to-date information to State and local Part H planners about issues that arise concerning relationships between the two segments;

[2] Sponsoring forums in which State and local planners would examine the ways in which their separate decisions are impacting on each other and wherein they would identify strategies to bring these issues to the attention of appropriate decision-makers for immediate consideration and action; and

[3] Creating opportunities for private providers, advocate groups and parents/consumers to share information about places where inconsistencies in State and local practices interfere with their responsibilities and/or roles in the Part H effort.

There will be many other activities that such committees could pursue, depending on the specific issues that are present in the State. *The important thing is to establish such a process as an integral part of the Part H planning initiative, as a means both to prevent and to redress problems associated with relationships between State and local jurisdictions involved with implementation of the Part H initiative.*

Finally, in order to bridge the gap between the work of these regional committees and the activities of the State Interagency Council [ICC] and lead agency, the chairs of all the regional committees in the State should be asked to serve on a newly appointed ICC Subcommittee. The charge given to this new subcommittee should be [1] to synthesize information about the issues and concerns being addressed in the regional committees about State/local relationships; [2] to develop strategies that might be used to facilitate better coordination between State and local planning activities; and [3] to ensure that a progress report be made at each monthly ICC meeting. In this way, clear lines of communication would be established between and among the many State and local actors involved in the Part H initiative.

DEVELOPING A COMMUNITY-BASED PART H SERVICE SYSTEM

It is likely that Part H service delivery systems will take on the characteristics of the community-based service systems for children with

special health care needs and their families that have been set forth as a national goal by the U.S. Surgeon General. Community-based systems of services have been described as "organized networks of integrated and coordinated services delivered at the local level" that are necessary to "insure that children with special health needs and their families receive the range of needed services in a timely fashion" [Campaign '88, U.S. Surgeon General's Conference]. The orientation of these community-based service systems is prevention as well as direct service, with a major emphasis on families. These characteristics of service systems closely approximate the service delivery system necessary to accomplish the Part H initiative successfully.

The focus of such service delivery is local communities wherein needed services are made available in as accessible a fashion as possible. The role of State agencies in such systems is facilitative, providing policy guidelines, resources and technical assistance as necessary.

THE NEED FOR ACTION

Persons with handicaps and their families are presently using services provided by Social Services, Education, and Health agencies in the local jurisdictions involved in this study. Interviews with parents lead to the inescapable conclusion that these programs are valued, and that they and their children benefit from their availability. As a result of federal legislation and a State Board of Education statute, the school systems are currently more active than the other agencies in providing categorical programs for children

with handicaps and their families. However, some of those individuals who meet income eligibility requirements also benefit from programs in the other agencies such as supported day care, respite programs, community nursing services, health clinics for those with handicaps, high risk infant follow-up programs, neonatal care units, and a variety of services offered to pregnant teenagers.

It is also evident that, within all of the local jurisdictions studied, there is a history of interagency cooperation and coordination that has resulted in the establishment of formal and informal linkages between and within Education, Health, and Social Services agencies. The interview data systematically indicate that these linkages have enabled personnel in those units to better serve all of their clientele. Referrals between agencies and programs, access to services, and follow-up activities have all been enhanced by these relationships.

Each of the local jurisdictions has also, over the years, established numerous interagency committees to deal with issues that affect all the agencies within a local jurisdiction. These committees usually involve representatives of all three agencies and the county executive's office as well as, in some cases, private organizations and parents. The work of these committees has enabled agency representatives to better understand both the challenges and the constraints confronted by other agencies in the local jurisdictions. Meetings of these local interagency committees have also resulted in facilitation of service delivery to children and families with

needs which are beyond the capacity or mandate of any single agency.

The existence of these elements produces a positive base upon which to build as the local jurisdictions consider how to proceed with implementation of Part H which provides for early intervention services for children with handicaps and their families. The major issue confronting the local jurisdictions will be how best to use the momentum created by these elements to develop the most effective early intervention services.

In order to address the question of how best to proceed with the implementation of early intervention services, there is a need to first consider the assumptions which serve as a basis for Part H. One assumption is that, in the long run, prevention will prove to be cost effective; that is, early intervention in the case of children with handicaps and their families will reduce their need for expensive and on-going services in the future. A second assumption is that a high percentage of these children will require services from more than one agency if early intervention strategies are to be maximally effective. A third assumption is that the integration of Health, Social Services, and Education agencies' efforts on behalf of children with handicaps and their families will reduce the need for duplication of services in the separate agencies.

In fact, while there is general agreement with these assumptions at a conceptual level, the pressing and extensive demands to deal with existing problems and crises of children and families in all public service agencies has led those agencies over time to allocate money and personnel to programs

which are focused on solving existing problems rather than preventing future problems. As the demands to solve existing problems have increased in number and complexity over decades, the agencies themselves have been organized into units which focus on the problem areas identified (i.e., special education, neonatal clinics, child protective services, etc.). The pressures to deal with these existing problems are exacerbated by the gap between demands for services and the resources available to provide those services. Thus, the personnel interviewed in all the agencies are confronted with the prospect of how to allocate their resources to prevent problems which *may* occur in the future, when those resources are already inadequate to deal with problems which *do* exist in the present. In view of these issues, it is not surprising that the local service agency personnel involved in this study view Part H with a high degree of ambivalence and concern.

There are four major areas which emerge from a review of Part H that will require the adoption of new, innovative strategies on the part of local agencies. The nature of the decisions about how to deal with these issues in each of the local jurisdictions [there is likely to be considerable variance from one locality to another] will be significantly affected by the structure and processes established in each locality to accomplish those tasks. Prior to presentation of recommendations regarding the structures and processes appropriate for dealing with Part H implementation, it will be useful at this point to review the four major areas that will require the adoption of strategies which generally differ from those in current use.

The first major area in which strategies will need to be considered has to do with the organization of an outreach effort. At the present time, most public agencies do not actively engage in outreach as a major part of their responsibilities. Some efforts do occur [i.e., health fairs, radio announcements for child find, etc.], but these are isolated instances rather than part of a systematic, comprehensive, coordinated effort to attract all of the individuals who may qualify for services. Some quotes which support this are "we do very little outreach" [Education]; "These are gray zone kids,...but there is no systematic outreach" [Health]; and "We wouldn't know what to do with them all if they were found" [Social Services]. Because of its prevention orientation, Part H is based on the assumption that all those who are potential problems must be reached at an early stage; and the only way to do this is to identify those who are not in the normal information channels as well as those who are. Outreach becomes a critical function of any prevention-oriented program.

The second major area focuses on speed of access to the service delivery system. Previous discussions have documented the length of time for access into the service system within the Education agency, but similar problems occur in Health and Social Services agencies. Some comments which support this are: "There are problems getting into the system...there is often as much as a four-month delay between when a child is identified...and the time that the child gets a [program] evaluation" [Health]; "It can presently take a while to get mental health resources for children" [Social Services]; and

"Delays [in access to services] have to do with availability of resources" [Social Services]. Given the intent of Part H to deal with potential problems as quickly as possible in order to avoid future problems, delays in assessment procedures or access to services would defeat the purposes of the legislation. Whatever system finally emerges to implement Part H, the challenge will be to insure speedy assessment procedures and access to services. As was indicated earlier in this report, a number of the parents of children with handicaps indicated that assessment processes sometimes took up to two years after the parents noted something "wrong" with their children's development.

Third, development of an interagency focus which facilitates coordinated service delivery to children and families with special needs and which encompasses two or more of the three agencies under consideration will prove to be a major challenge. Among the many comments related to this issue made by those interviewed are the following: "Each agency must place a high priority on the interagency activity...synergism is the key concept" [Health]; "Coordination will be difficult...there is a lot of tunnel vision involved...territorial issues...who has what responsibility" [Education]; and "When it comes to sharing, it could be a problem...we don't want to take a lot of responsibility for their [other agencies] cases" [Social Services]. As is evident from these remarks and many others that were made, a number of issues will arise as interagency activity is attempted. Resolution of these issues will, of necessity, need to deal with the building of trust among personnel with differing professional orientations, the development of viable decision-

making processes which enable consensus-building, and the definition of roles that personnel engaged in the Part H activity are expected to implement.

Fourth, adoption of the family focus required by Part H will require considerable reorientation for agency personnel who are currently used to dealing with the symptoms manifested by a single client. The assumption in Part H that treatment of a child with handicaps cannot be maximally effective without also impacting on the environment in which that child is situated will require a broader perspective on the part of agency personnel than is currently the case. As was noted by some of those interviewed, "Under 457 we will have to get a broader assessment and shared areas of expertise for assessment...this goes beyond what we have established for the 0-3 State law" [Education]; "The problems of these children require more than our program" [Mental Health]; and "We've got to straighten out how these programs relate" [Social Services]. There is no doubt that there will be an increase in the complexity of assessment, service delivery, and coordination as the family focus emerges.

RECOMMENDATIONS

Recommendations for local jurisdictions regarding the implementation of Part H fall into these categories: planning issues, selection of a lead agency, building a coalition to provide support for the lead agency within the individual Education, Social Services and Health Departments, conflict resolution issues, and resource needs.

The County Executive should appoint an ad hoc planning committee for the purposes of recommending [1] creation of a policy-making Part H council to oversee Part H efforts, [2] a local lead agency, and [3] the general responsibilities of these units.

Part H will require the enthusiastic involvement of all local service agencies in a locality if a viable early intervention system is to evolve. Interviews with agency personnel in the six local jurisdictions elicited numerous comments which indicate that there is wide-spread disagreement among the agencies over which should be the local lead agency. This disagreement was most evident between the Health and Education agencies. Regardless of which agency is selected, some dissension and mistrust is likely to result. The most important fact to note, however, is that no single agency will have sufficient levels of trust, confidence, and support from the remaining agencies to insure that other agencies will voluntarily consider the necessary changes in resource allocations, resource utilization, policies, and programs required to implement an effective early intervention system for Part H clients.

In fact, the definition of the nature of an early intervention system is really the responsibility of all the local service agencies, since it will result in changes *within* each of them as well as *between* them. In order to structure the policy making function under such circumstances, local jurisdictions should establish a Part H Council that is charged with developing agreement about the best ways of achieving and implementing the desired changes, within the framework of local jurisdictional policies and

guidelines. The Part H Council needs to function as a collaborative interagency arrangement; a summary of the conditions required for collaboration can be found in Appendix B. In this way all of the affected parties have equal opportunity to influence the nature of the overall policies as well as equal responsibility for their implementation. *The Part H Council would then serve as the policy body for whichever unit [in one of the service agencies or in the county executive's office] is assigned lead agency status.* The individual in the local lead agency assigned responsibility for administration of the Part H initiative would then serve as staff to the Part H Council. The selection of the local lead agency would be based on criteria established by the Ad Hoc Planning Committee.

Once these responsibilities have been discharged, the Ad Hoc Planning Committee will have completed its assigned task and should be disbanded.

> **Criteria for selecting a local lead agency should include [1] the extent to which a given unit is in the position to adequately represent the philosophic orientation underlying Part H and [2] the extent to which a unit is willing to serve as a facilitator for integration and coordination of services by all the local service agencies.**

As was discussed previously, the early intervention orientation of Part H is based on a set of assumptions that provide a framework within which the Part H Council and the local lead agency must operate. The decision as to whether the lead agency should be the Education Department, the Health Department, the Social Services Department, or a unit created in the County Executive's office may vary from one local jurisdiction to another; the

primary consideration should be based on which is most likely to support the orientation behind Part H. The second major issue in the determination of a local lead agency focuses on the ability of a given local agency to facilitate development and implementation of an integrated and coordinated service delivery system. Accomplishment of this task will require that the local lead agency have the confidence and trust of the other agencies with which it must collaborate. Adequate staff must be assigned to the lead agency to insure a reasonable level of effectiveness in the endeavor, and those individuals must have a primary commitment to the early intervention process.

In order to provide a forum for discussion and resolution of the major issues related to Part H, the composition of the Part H Council should include representation by all affected parties.

Representatives from all of the local service agencies, private sector providers, and parents should serve on the Part H Council. The comprehensive integrated early intervention service delivery system required for implementation of Part H is most likely to be achieved if major initiatives of the local lead agency are authorized by consensus among the Part H Council members. Moreover, the use of the Part H Council for consensus-building will enhance trust levels between all parties involved, and provide the basis for the high commitment levels required for successful implementation. Implementation of Part H is likely to require a number of innovative initiatives on the part of the local lead agency, and some will work better than others. A high degree of support on the part of the contributing agencies will be required during the early years to create and implement

policies and practices that will result in the establishment of an effective early intervention system. This same high level of support will be required in later years to maintain the early intervention system at a high level of effectiveness, as all local agencies inevitably face increasing demands on their resources. The policies established by the Part H Council will dictate the roles and responsibilities of the local lead agency unit which assumes implementation responsibility for Part H initiatives.

Agency representatives who serve on the Part H Council must also serve as active advocates of the early intervention process within their own agencies.

In this role agency representatives must have policy responsibility and decision-making authority over resources within their respective agencies in order to facilitate implementation of decisions made in the Part H Council. The most appropriate agency representative to the Part H Council are the directors of local service agencies or their designees.

ACTION STEPS

Once the recommendations referred to above have been dealt with, there will be numerous activities that will have to be undertaken. Some of these activities will be specific to each locality, and others will be required in all localities, although the order in which they are addressed may vary. The more critical action steps that local lead agencies will have to address are presented below.

First, the Part H Council, working collaboratively with the local lead agency personnel, will have to develop strategies for resolving territorial,

policies and practices that will result in the establishment of an effective early intervention system. This same high level of support will be required in later years to maintain the early intervention system at a high level of effectiveness, as all local agencies inevitably face increasing demands on their resources. The policies established by the Part H Council will dictate the roles and responsibilities of the local lead agency unit which assumes implementation responsibility for Part H initiatives.

Agency representatives who serve on the Part H Council must also serve as active advocates of the early intervention process within their own agencies.

In this role agency representatives must have policy responsibility and decision-making authority over resources within their respective agencies in order to facilitate implementation of decisions made in the Part H Council. The most appropriate agency representative to the Part H Council are the directors of local service agencies or their designees.

ACTION STEPS

Once the recommendations referred to above have been dealt with, there will be numerous activities that will have to be undertaken. Some of these activities will be specific to each locality, and others will be required in all localities, although the order in which they are addressed may vary. The more critical action steps that local lead agencies will have to address are presented below.

First, the Part H Council, working collaboratively with the local lead agency personnel, will have to develop strategies for resolving territorial,

work over an extended period of time will evolve *only if* there is adherence to the established "rules of the game." While there is absolutely no way to insure that any individual or agency will "win" all of the time, or even some of the time, it is imperative to insure that each individual and agency perceives that a fair opportunity to present a position was given, that the final resolution to any disagreements occurred in a fair manner, and that the same agreed-upon procedures were used to resolve all contested issues.

Fourth, the inclusion of parents of children with handicaps on the Part H Council [as is also the case with the ICC at the State level] is critical both for its symbolic value and its substantive value. Parental involvement at the policy level on an equal basis with agency representatives will signify to the entire community of families having members with handicaps that the local jurisdiction is serious about addressing their needs. At a substantive level, the parents will introduce a perspective about the issues that will require serious consideration as efforts to implement Part H proceed.

It is suggested that the parents of children with handicaps appointed to the newly created Part H Council be selected initially from the leadership of established community organizations which serve as advocates for the handicapped. In order to insure full, active, and continuous involvement of the parent members, some support may have to be provided to parents, depending on the nature of their personal circumstances. Among the types of support which should be considered are: [1] transportation to and from meetings; [2] reimbursement for child care while attending Council-related functions; and

[3] scheduling meetings so they do not always conflict with parent work schedules.

Fifth, the development of general goals, objectives, and a time schedule for task accomplishment should be undertaken as soon as possible. Although the schedule may undergo some adjustment as the Part H Council and local lead agency proceed with their efforts, the existence of such a schedule will insure a sense of urgency on the part of everyone involved and also serve as a tool for identifying problem areas as efforts to establish an early intervention system progress.

Sixth, as indicated in the legislation, central components of the early intervention system are the establishment of a team that will be responsible for developing the IFSP and determination of elements of the IFSP. For many of the agency personnel interviewed, this task was viewed as overwhelming; they had no idea as to where to begin. In fact, the State lead agency, in conjunction with the ICC, has awarded five grants to localities in all areas of the State to develop and test model IFSP procedures during the 1988-89 planning year. In each of the five localities, a specific individual has been assigned as director of the grant and a variety of local service agencies are administering these grants.

Local lead agency personnel should contact the grant directors in the areas nearest their localities to determine: [1] the nature of the model being tested; [2] the strengths and weaknesses of the model(s) that have emerged; [3] the nature and amount of resources required to implement the model; [4]

the nature and impact of territorial, political, and resource issues that have emerged (as well as how they were resolved); and [5] recommended changes in the model that is being tested. This information will provide the local lead agency and the Part H Council with sufficient information to begin considering the most appropriate procedures for establishing early intervention services within the locality. Additionally, once the grants have been completed, the State lead agency will provide information to all local jurisdictions about all the models tested and their relative utility under varying sets of local conditions.

In the last section of this report, a brief description is provided of technical assistance activities for Part H planners that respond to some of the concerns expressed by participants in this study.

TECHNICAL ASSISTANCE FOR PART H PLANNERS

This research was conducted as an overall examination of the ability and readiness of the State and localities to implement Part H of P.L. 99-457 as of the second year of the planning cycle defined in the legislation. The technical assistance activities suggested by the findings in this study fall into three categories: [1] the development of appropriate structures for dealing with intra-agency and interagency issues associated with Part H; [2] the establishment of processes that would enable these structures to be used effectively; and [3] the creation of those conditions that would enable the desired processes to have their intended outcomes and effects.

THE NEED FOR TRAINING

Given the need to establish community-based early intervention service delivery systems for infants and toddlers with handicaps and their families, States and their constituent localities are confronted with unprecedented demands for interagency collaboration which will lead to this desired end. The Part H mandate is unique in the fact that its implementation will necessitate: [1] significant pooling of resources by involved agencies at both the State and local levels; [2] the establishment of an agreed upon interagency goal; and [3] commitment to a prevention orientation in the Part H service delivery system.

The implications of these requirements for State and local service agencies include the possible need to develop policies and practices that will be in conflict with those which currently exist within these organizations. Confronting these needs will require changes within the agencies with respect to what they do and how they do it. There are a number of characteristics of an early intervention system for infants and toddlers with handicaps and their families that will test the service agencies' abilities to develop and administer a prevention-oriented program. They include:

- o creation of effective outreach programs that will substantially broaden the traditional clientele of these agencies;
- o development of methods of funding programs and services that are collaborative in nature;
- o maintenance of a prevention orientation within agencies that ordinarily deal with crises or immediately compelling client problems;

- o creation of procedures which will facilitate identification, assessment and treatment of special needs infants and toddler and their families more quickly than is now the case; and

- o the need to view *both* infants and toddlers with handicaps and their families as the clients of the service system.

Essentially, the service agencies now operate by allocating the demands made upon them in a manner which conforms to existing resources, while a prevention orientation dictates the allocation of resources to satisfy manifest needs. The differences between resource driven agencies and need driven agencies are considerable.

TRAINING ACTIVITIES TO MAKE COLLABORATION WORK

In order to collaborate successfully, State and local agencies need [1] to increase their capacities to design structures that enhance collaboration, [2] to institute operational procedures that would enable these structures to work effectively and [3] to enable these desired procedures to be used effectively. Training to accomplish each of these objectives is described below.

Building Collaborative Part H Structures

Attempts to create units within the existing service agencies that will be responsible for developing policies, procedures and practices leading to implementation of Part H are unlikely to be successful. A single prevention-oriented unit within a larger unit which is basically maintenance driven will consistently find itself unable to operate with the flexibility and freedom required. It can also be anticipated that no single service agency or unit within an agency will have sufficient influence with other agencies and units

that are highly protective of their own prerogatives and mandates. Finally, no single unit within a larger agency is likely to have the authority to allocate and reallocate resources as needs emerge.

These issues will confront all service agencies at the State and local levels as they attempt to develop structures which will enable them to cope with the requirements of Part H. Therefore,

> **State and local service agencies will need training that enables them to identify and implement collaborative organizational structures appropriate for establishing prevention-oriented community-based Part H service systems.**

Such training must, of necessity, enable State and local agencies to develop realistic and appropriate strategies to accomplish the following:

- o portray the type of organizational structure that will best facilitate development of the Part H early intervention system;
- o demonstrate how such a unit would be organized and staffed;
- o determine how the resources required by such a unit could be allocated, and what the possible sources of these resources are;
- o formulate policies and define practices that will have the support of all agencies involved in the interagency effort;
- o identify those individuals who need to be involved in the development of policies appropriate for a collaborative interagency initiative; and
- o examine how such a unit could facilitate implementation of the interagency policies that are established.

Consideration of these issues and, quite naturally, strategies that address them leads to the need for understanding the processes that will result in effective implementation of a collaborative interagency effort.

Operational Procedures That Support Part H Collaboration

A primary requirement for effective implementation of a prevention-oriented interagency initiative designed to serve infants and toddlers with handicaps and their families is the ability to achieve a reasonable level of consensus among those charged with the responsibility for determining Part H policies and overseeing their implementation. Consensus is required to insure that a high level of commitment to implement Part H early intervention services will occur among personnel from different agencies which have different mandates.

Unless such commitment is developed, the most likely result will be rhetoric which supports the notion of a Part H early intervention system, accompanied by agency behaviors that impede the effective implementation of such a system. Interagency politics, curtailment of needed services and the emergence of territorial protection efforts are the most common outcomes of an inability to develop mutually acceptable bases for action. To insure that opportunities for building consensus emerge within units established to oversee implementation of Part H,

> **Training should be provided which will enable State and local agency personnel with responsibility for implementation of Part H to interact in ways that identify mutually acceptable solutions to issues confronting the interagency unit.**

This training should result in a more effective interagency unit in which involved personnel gain increased capacity to accomplish the following:

- o establish procedures which would ensure that realistic opportunities for consensus-building emerge;

BEST COPY AVAILABLE

- o select personnel for the interagency unit who will be effective in the consensus building role;
- o adopt operational procedures appropriate for implementing those decisions that emerge from the collaborative process.

The success of consensus building strategies for a collaborative interagency effort will depend upon the existence of conditions that foster trust and mutual respect among all agencies involved in the Part H enterprise.

Conditions Required For Collaborative Implementation of Part H

The emergence of trust and mutual respect among members of the Part H interagency effort is dependent upon the utilization of strategies directed to that end. Trust is not a condition that simply "happens." Rather, in those interagency units where its existence is evident, trust is the result of carefully planned tactics designed to achieve that effect.

The use of strategies which lead to the emergence of trust and mutual respect requires an intensive effort to regulate the ways in which decisions are made within the collaborative unit. Based on the need to establish conditions which will provide an appropriate base for the emergence of trust,

Training should be offered to permit State and local service agency personnel, involved in the implementation of Part H, to establish those conditions which will facilitate Part H interagency collaboration.

Upon completion of such training, personnel responsible for implementation of Part H at State and local levels of government should have strengthened their skills to:

- o use information sharing techniques and decision making processes in ways that contribute to building trust and mutual respect;

- o employ appropriate techniques for reducing the impact of constraints imposed by individual agencies on interagency planning and actions; and

- o engage in activities that reduce the likelihood that single agency territorial issues will impede interagency progress.

These skills are necessary for agency personnel as they accept the challenge of the Part H initiative to establish community-based early intervention service systems. They will be essential for agency personnel as they cope with the shift to prevention, family support and interagency collaboration necessitated by the Part H legislation.

Summary

Providing technical assistance that satisfies these recommendations will permit agencies at the State and local levels to engage in collaborative interagency activities leading to effective implementation of Part H. Program and service delivery will have to occur within units that require intensive and extensive interactions on a continuing basis over an extended period of time. The considerable degree of agency interdependence required in such units is a function of the need to accomplish an objective that no single agency can accomplish independently. The more typical approach of establishing coordinating structures from which agency disengagement is a simple process will be ineffective to implement the Part H service delivery system.

The use of interagency collaboration to plan and implement Part H services and programs is equally important at the State level and in local jurisdictions. The same processes and techniques will need to be used. The

outcome at the State level would be the formulation and implementation of a State wide policy that ensures the development of early intervention services in local jurisdictions. The outcome in local jurisdictions would be the development of an accessible community-based service delivery system with a prevention orientation for infants and toddlers with handicaps and their families.

TRAINING ACTIVITIES THAT FACILITATE STATE/LOCAL COORDINATION

Part H planning must also attend to the ways in which State-level activities and local level activities relate to each other. The mission of Part H is complex and imposes many hardships on planners operating in local jurisdictions as well as those who work at the State level. Successful implementation of Part H will depend on the development of clear communication channels that would be used to share information and resolve issues that arise from a lack of coordination between the two governmental sectors. Coordination requires the use of different interagency techniques and behaviors than are used with collaboration. See Appendix B for a discussion of the differences between these two kinds of interagency efforts.

Establishing Structures That Enable Coordination

State and local agencies concerned with implementation of Part H share an enduring need to be mutually supportive of each other. The basis of this need is recognition of the fact that neither is likely to be effective in achieving its Part H mission unless there is acceptance of the role each plays in the Part H enterprise and efforts are made to deal with the issues

confronting agencies at both levels. The development of a structure that facilitates satisfaction of these needs is essential to insuring coordination of State and local Part H efforts.

A coordinating structure is appropriate [1] when the purpose that it serves is relatively focused and specific; and [2] when accomplishment of that purpose does not require individual agencies to relinquish their autonomy in seeking to accomplish the interagency objective. Promoting facilitative relationships between State and local Part H planners is just such an interagency objective. Therefore,

> **Training should be provided which enables State agencies to identify and activate organizational structures appropriate for ensuring effective coordination of State Part H initiatives with Part H activities in local jurisdictions.**

The development of structures which permit coordination on the part of State and local Part H planners will enable them to address the following interagency concerns:

- o creation of a method by which information sharing between and among concerned parties in State agencies and local jurisdictions would occur;
- o establishment of organizational structures that permit State and local agencies to influence each other in mutually supportive ways; and
- o delineation of procedures that would be used by the coordinating unit to enable State and local Part H planners to understand their common concerns and to take steps to address them.

Operational Procedures That Support Coordination

The procedures necessary to maintain a successful coordinating unit that enables Sate and local Part H planners to understand and influence each other are necessarily different from those required to maintain a collaborative, consensus-building interagency unit, such as the local Part H Council described earlier in this report. Establishing facilitative relationships between State and local agencies as major planning initiatives are undertaken is vital to the ultimate success of such enterprises. Part H is no exception. Therefore,

> **Training should be provided which will enable State and local Part H planners to establish mutually acceptable procedures for promoting positive relationships between the two governmental sectors.**

The use of mutually acceptable processes that enable Part H planners to develop positive working relationships in responding to the Part H challenge would allow State and local agencies to address the following concerns:

- o confirmation of types of information that must be shared, as well as appropriate techniques for disseminating that information, in order to permit effective State/local coordination of Part H planning;
- o establishment of decision making processes in the interagency unit that are appropriate for coordination and that do not require the development of consensus to obtain agreement; and
- o definition of appropriate interagency objectives that can be accomplished through State/local coordination.

Developing procedures that would be used to coordinate State and local Part H planning initiatives requires far less agency interdependence than is needed

for the collaborative interagency initiative required to implement Part H by State and local agencies.

Conditions Required To Support Coordination

If the structure and processes of coordinating units that will facilitate information-sharing among State and local Part H planners are different from those required for collaborative interagency efforts, it logically follows that a different set of conditions must be established to facilitate such information sharing and coordination. Based on the need to establish conditions appropriate for such purposes, it is recommended that

> **Training should be provided which will permit State and local Part H planners to establish conditions which will facilitate coordination between agencies at both levels.**

In establishing productive working relationships for the Part H initiative, it is quite clear that State and local Part H planners will demonstrate primary loyalty to their home agencies rather than to the interagency unit; this is in contrast to collaboration which requires that primary loyalty be shown to the interagency unit. Recognizing this fact, it is incumbent on representatives of agencies on both levels to seek solutions to issues that will be mutually beneficial and to accept viable compromise when appropriate. The training must enable local and State Part H planners to

- o establish conditions that permit agencies at both levels to mutually influence each other;
- o develop strategies to identify and satisfy those common interests and concerns;
- o create conditions that enable agencies to satisfactorily resolve areas of disagreement in a timely fashion; and

- establish conditions that permit active sharing of information between State and local Part H planners.

THE TIME IS NOW

At this moment in time, States find themselves in year two of the five-year planning period defined in the Part H legislation. Required State wide policies are being generated and some planning issues are being decided. Energies must now be devoted to translating State level policy decisions into viable community-based service systems for infants and toddlers with handicaps and their families.

The technical assistance issues outlined in this section of the report focus on enhancing State and local agencies' capacities to collaborate and to improve communication between State and local Part H planning communities. They would be of particular use to States and local communities at this point in the Part H planning process.

CONCLUSIONS

There are three overarching conclusions that were derived from this study. First, Part H service delivery systems must be constituted differently if they are to meet the challenges presented by the legislation. Second, it is not clear that the federal government understood the extent to which change would be required by State agencies and local service providers in order to meet these challenges fully. Finally, enhancing State and local planners' capacities to engage in collaborative interagency activities will be the single most important factor in achieving the Part H mission.

APPENDIX A

EXECUTIVE SUMMARY: STATE PROFILE OF INTERAGENCY EFFORTS

This report presents findings from the first stage of a study of the nature of State interagency efforts on behalf of children with special needs and their families. The research is sponsored by the Bureau of Maternal and Child Health and Resources Development, U.S. Department of Health and Human Services, and was conducted as a subcontract to the National Center for Networking Community Based Services at the Georgetown University Child Development Center.

Intent Of The Study

The intent of the study was to examine the ways in which interagency efforts by State and local government agencies influence accessibility of services for children with handicapping conditions and their families. The following issues are addressed: [1] What is the nature of interagency efforts on behalf of children with handicaps at the State level?; [2] How have local service agencies, or their representatives, been involved with State Part H interagency planning and actions?; and [3] What issues will need to be addressed in order to synchronize Part H interagency efforts at the State level with Part H interagency efforts in local jurisdictions?

Site For The Study

The research was designed as an in-depth case study of a mid-Atlantic State that has 24 local political jurisdictions with a wide range of demographic characteristics. They range from densely populated urban jurisdictions to large and medium size suburban localities to small sparsely populated rural areas. The State was chosen for the study because of its long standing progressive attitudes toward providing services to persons with handicapping conditions and because of the value it places on interagency efforts to deal with issues related to that population.

These attitudes have been expressed through the development by State agencies and executive offices, and their local counterparts, of a wide range of programs for persons with disabilities and their families. The value that the State places on interagency efforts was in part translated into the establishment of at least three formal committees charged with the responsibility of improving the provision of integrated services and programs for this targeted population. The development and operation of these three

State Interagency Committees was the focus of this report which presents a profile of State interagency activities. This information is now being used to structure data collection activities in selected local jurisdictions in the State.

Research Procedures

This study is to be conducted in two stages. In stage one, selected personnel from all of the major State Departments and Executive Offices that are involved both directly and indirectly with planning or programs for children with handicaps and their families were interviewed. Respondents held positions of responsibility for policy, program development and/or coordination of services for this targeted population. Thirty persons were interviewed between November 1987 and April 1988. In addition, participants were involved in verification of the data both through attendance at a meeting scheduled to enlist feedback about the preliminary report and through a series of phone conversations and meetings with persons who were unable to attend.

Several documents were also reviewed, including: State agency policies and Executive Orders; State and federal legislation; interagency plans; descriptions of interagency programs sponsored by the governmental units; information and minutes of State interagency committees, subcommittees and task forces; and descriptions and budget analyses of single agency programs for children with handicaps and their families. Where possible, the researchers attended meetings of the State Interagency Committees under study. Information from these documents and meetings was used both to verify data provided by respondents and to develop this report

Features of Interagency Efforts

The framework used for analysis of the three State Interagency Committees was developed by ICA and represents a compilation of data from a series of studies and technical assistance activities conducted over the past decade in order to identify critical factors that contribute to successful interagency relationships.

Interagency efforts can be characterized as cooperative, coordinative or collaborative. Each of these interagency types represents an increasing amount of interdependence on the part of single agency participants. Planners make decisions about which type of interagency arrangement they will use depending on the specific purpose that the interagency effort is intended to accomplish. In brief, collaboration may not always be the most appropriate strategy for agencies to adopt; depending on a set of circumstances that are described in detail in report, successful interagency activities may also be

accomplished using either a cooperative or a coordinative approach. [See Appendix B for further discussion of this conceptual framework]

The organizational conditions and interpersonal relationships that characterize each interagency type are distinctly different. They are described in this study in terms of the following features: [1] interagency objective; [2] interagency policies; [3] interagency structure; [4] resources; [5] loyalty to the interagency effort; [6] procedures to establish agreement; [7] decision making processes; and [8] roles of key personnel. The three State Interagency Committees were examined to determine the extent to which the nature of each interagency effort is appropriate for the purpose toward which it is directed.

Findings

The three State Interagency Committees under study were: the State Coordinating Council for Residential Placement (SCC); the Interagency Planning Committee for Children (IPCC); and the Interagency Coordinating Council (ICC).

The SCC was established in 1982 by Executive Order as a part of State implementation of P.L. 94-142 in order to provide an interagency vehicle through which State agencies could make effective residential placements. Its current membership includes the State Department of Education (SDE), the Department of Health and Mental Hygiene (DHMH), the Department of Human Resources (DHR) and the Juvenile Services Administration (JSA). The SCC operates as almost a classic coordinative interagency arrangement. Agency members of the Council express satisfaction with its ability to accomplish its interagency objective successfully.

The IPCC was appointed in 1985 by the Governor to streamline State services for children with special needs through the development of interagency efforts. This mission was very broad and required major changes in the current operations of participating units if it was to be accomplished successfully. Initially, IPCC activities were very energetic and a comprehensive Interagency Plan was submitted by the Committee to the Governor in 1986. At the present time, the IPCC is relatively inactive; a partial explanation for this inactivity may be found in the nature of the interagency features of this Committee. While the IPCC was charged with a mission that required collaboration, the organizational conditions under which it now operates and the nature of the interpersonal relationships of Committee members are best characterized as approximating either cooperative or coordinative interagency efforts.

The ICC was established in 1987 by Executive Order as a part of State planning for implementation of Part H of P.L. 99-457 in 1992. Council members include representatives of the four major State agencies (SDE, DHMH and DHR),

as well as the Governor's Office For Children and Youth (GOC&Y), private providers, advocates and parents. Its purpose is to advise the Lead Agency (i.e., GOC&Y) in the planning of a comprehensive coordinated system of delivery of early intervention services to infants and toddlers with handicaps and their families. In effect, the ICC is actively pursuing its mission; the actions taken by the Council address both issues specific to the legislation and the development of procedures that will define the nature of the interagency effort. Since the ICC is only nine months old, it is premature to attempt to classify it as a specific type of interagency effort. The interagency objective for which it is responsible clearly requires a collaborative interagency effort. At this point in time, the ICC appears to be developing the organizational conditions and interpersonal relationships that will enable collaboration to occur. Continued attention to those interagency features that will lead to collaboration is needed. As the ICC matures (in terms of operation), the specific needs that will have to be satisfied to ensure collaboration will become more evident.

Implications For Part H Interagency Efforts

A number of substantive issues have emerged from stage one of the study that have important implications for interagency efforts associated with Part H of P.L. 99-457. First, collaboration is not always an appropriate interagency strategy; more often than not a cooperative or coordinative effort will suffice to accomplish a particular interagency objective. Second, successful interagency efforts are dependent on the extent to which planners create organizational conditions and interpersonal relationships suitable to accomplish the interagency objective. Third, effective State interagency committees have the authority to make policy decisions about the interagency effort; confining the committee to an advisory role seriously impairs its ability to plan and develop integrated service delivery systems. Fourth, when implementation of legislation requires considerable agency interdependence, selection of a lead agency is of primary importance and should include an assessment of that agency's capacity and willingness to facilitate State-wide interagency planning and actions. Fifth, the effectiveness of State interagency planning and actions is largely dependent upon the development of appropriate relationships between Part H interagency councils and the lead agencies in each State. Finally, the nature of State interagency planning and actions will influence the effectiveness of interagency activities in local jurisdictions.

These issues have the following implications for State level planning for implementation of Part H:

- State Part H interagency councils will need to be configured as collaborative interagency efforts.

o State Part H planners will need to devote immediate attention to the creation of organizational conditions that foster successful interagency collaboration at the same time as they address more substantive program issues.

o Part H interagency councils should be assigned a policy role in the development of State-wide coordinated systems of early intervention services for infants and toddlers with handicaps and their families.

o State lead agency responsibility should be assigned directly to the Part H interagency council. By extension, federal Part H planning grants should be administered by the council.

o Establishing a lead agency other than the council enhances the difficulties of creating conditions for collaboration. In such cases, the relationship between the lead agency and the Part H interagency council must be clearly delineated. The likelihood of conflict between the lead agency and the council will be reduced if policy authority is shared by the lead agency and the council.

o The ways in which State interagency efforts can influence accessibility of services at the local level need to be defined early on and made an integral part of the State Part H planning process.

APPENDIX B

FEATURES OF INTERAGENCY EFFORTS

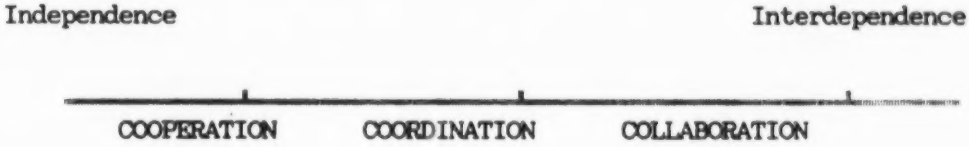
It is relatively common for words to be used rather loosely in our society; words are dispensed with the belief that others share similar definitions and understandings of the concepts to which reference is made. When, as is often the case, those shared understandings do not exist, the result is frequently confusion and distrust. This "frame of reference" problem is much more common than is generally realized. Examples of some terms for which there are a variety of conceptual understandings are: professional; intelligence; effectiveness; supportive; authority and participation.

A similar conceptual problem exists with respect to the term collaboration. Typically, the terms cooperation, coordination and collaboration are used interchangeably in describing interagency activities. In this study these terms are used to describe distinctly different types of interorganizational relationships.

In reality, there are a number of different approaches that may be adopted in establishing interorganizational relationships. These approaches can be depicted along a continuum ranging from limited single agency dependence on other agencies to accomplish a specific objective, to a state of interdependence among agencies engaged in accomplishing a common objective. This continuum is depicted in Figure 1 below.

Figure 1

Interdependence In Interagency Efforts



Cooperation is an interagency effort that requires the least amount of interdependence between individual agencies. Collaboration, on the other hand, requires the greatest amount of agency interdependence.

There are a number of different organizational and interpersonal issues that cause single agencies to move from independent modus operandi to the

adoption of interdependent strategies to accomplish common objectives. Cooperation, coordination and collaboration are characterized by different organizational conditions and interpersonal behaviors. The discussion of each interagency type that follows describes the characteristics of the three types of interagency efforts (i.e., cooperation, coordination and collaboration) according to the following features: [1] interagency objective; [2] interagency policy; [3] interagency structure; [4] resources; [5] loyalty to the interagency effort; [6] procedures for reaching agreement; [7] interagency decision making; and [8] personnel roles.

Typically, interagency efforts do not conform completely to any of the three prototypes (e.g., cooperation, coordination and collaboration); rather when they work, they tend to approximate most of the organizational conditions and interpersonal features associated with a particular type.

Cooperation

Cooperation is identified as occurring when an agency perceives that it can better accomplish one of its own objectives by working with other agencies that have a similar objective to accomplish. These agencies decide to undertake a collective activity to meet their common objective because it is in each of their own best interests to do it that way.

Interagency objectives which are achieved through cooperation usually have a narrow focus and require minimal or only short-term commitment of the agencies and personnel involved. An example of an objective which requires cooperation to accomplish is the organization of a conference jointly sponsored by more than one organization or unit. Commitment to the interagency effort is over when the conference is over.

In effect, cooperative interagency efforts do not disrupt or interfere with standard operating procedures in the participating organizations. Therefore, there is no need for agencies to create any ***interagency policy*** about the effort. Moreover, existing agency policies will not need to be modified. In planning a conference, agencies will basically follow their regular procedures for running conferences, although decisions about the content or speakers or location may be made with their partners in the interagency activity. The planning period may be as brief as a few weeks or as long as a year, but rarely longer.

By extension, unlike more interdependent forms of interagency efforts (e.g., coordination or collaboration), agencies do not need to create a new ***interagency structure*** to accomplish their common objective. The conference itself is a clearly definable objective and the need for interagency action is complete when the conference is over and the administrative actions which follow have been taken.

The nature and source of ***resources*** provided to support the interagency relationship is another feature that discriminates among the three kinds of interagency arrangements. Appropriate agency resource contributions to interagency efforts may include personnel, programs, facilities and monies. Cooperative interagency arrangements are supported with discretionary funds which remain within the control of the individual agencies. For example, participating agencies contribute resources to the joint conference on an as-needed basis through a process of on-going negotiation. Additional funds are provided only to the extent that individual agencies are willing to do so when requested.

In cooperative interagency arrangements, no ***loyalty to the interagency effort*** is required. Rather, participant loyalty is to the individual agencies. Because the collective objective is confined to a narrowly defined activity, conflicts about legitimate single agency prerogatives and appropriate interagency responsibilities rarely surface. Therefore, cooperative efforts work well without the development of procedures for ***establishing agreement*** among participating agencies. The need to resolve conflicts over territorial issues becomes increasingly more important as interagency efforts become more and more interdependent. On the other hand, conference planning can be successfully completed without participant loyalty to the interagency effort and without establishing conflict resolution procedures.

Interagency decision making is another key factor in the development of successful interagency relationships. In cooperative arrangements, interagency decisions are appropriately made by the single agencies. The situation is constructed such that single agency needs take priority over interagency needs. The decision to jointly sponsor a conference can be made through normal organizational decision making processes. Individuals working on the conference are empowered to act only within the framework of decisions made within their individual agencies. In addition, little or no need for information sharing among agencies exists in order to plan and run the conference; each agency simply shares information about its own organizational needs that the conference is intended to satisfy.

Agency ***personnel*** involved in the three types of interagency efforts are required to play different ***roles***. Cooperative interagency efforts are carried out by personnel whose primary function is to represent their individual agencies' interests. They are assigned responsibilities for accomplishing the interagency task on a short-term basis. Their supervisors usually consider that their involvement in the interagency activity is a part of their regular assignment.

In sum, little creative effort is required to plan and carry out a cooperative interagency effort such as a joint conference. Rather, it is largely an administrative process of deciding how best to meet previously

established organizational needs within the budgetary and time constraints which prevail. Essentially, single agency needs are being met using a cooperative administrative process that involves sharing the work and benefits with another unit or organization. For these reasons, joint conference planning and implementation can best be accomplished using a cooperative interagency effort. Cooperation is an important interagency arrangement that may be used quite successfully in the accomplishment of interagency objectives that require minimal amounts of interdependence. Table 1 below depicts the features of cooperative interagency efforts:

Table 1

Features of Cooperative Interagency Efforts

OBJECTIVE:	the interagency objective has a narrow focus, and is short-term
POLICY:	no interagency policies are needed
STRUCTURE:	no new interagency structure is required; specific agency personnel are assigned to achieve the objective
RESOURCES:	supported with discretionary funds which remain within the control of the individual agencies
LOYALTY:	no loyalty to the interagency objective is required; loyalty is to the individual agencies
AGREEMENT:	no major single agency territorial issues arise; agreement is not an issue
DECISION MAKING:	interagency decisions are made by the single agencies; individual agency needs are primary; interagency needs are secondary
PERSONNEL ROLES:	carried out by personnel whose primary function is to represent their individual agencies' interests and who are assigned responsibility for the interagency effort on a short-term basis

Coordination

Coordination occurs when two or more agencies agree to formally enter into an interorganizational arrangement to accomplish some common objective. Coordinative interagency efforts are often appropriate when individual agencies are required to work together by some administrative office with

higher authority, or as a result of regulations associated with federal, State or local policy mandates. Coordination may also be used successfully when agencies decide voluntarily that a common objective can not be accomplished independently within existing budgetary and time constraints, and/or that each is unwilling to accept the internal problems which would accompany any concentrated effort to reallocate resources for that purpose. Whether the motivation for collective action is mandated or voluntary, primary interest, as was the case with cooperation, is directed toward addressing the needs and concerns of individual agencies through the use of a coordinative administrative strategy.

Interagency objectives that are best accomplished with a coordinative interagency effort tend to be broad issues that require considerable commitment of the agencies and personnel involved. These objectives are usually more complex than those best served by a cooperative interagency effort. An example of coordination takes place when a mental health agency, an education agency and a juvenile services agency, which have responsibility for providing services to a targeted population such as high school drop-outs, agree that by working together each is likely to be more effective in delivering services to this clientele. In addition, they agree that the interests of their respective agencies are likely to be better served by adopting a coordinative strategy for reducing the number of school leavers. Commitment to this effort is likely to be sustained over a period of years.

Coordinative interagency arrangements require a moderate departure from standard operating procedures by participating agencies. To accomplish the collective objective, agencies must make a formal commitment to the interorganizational activity. This often entails changes in the ways that single agencies provide services or programs that accommodate the special needs of the population targeted for services by the interagency effort. As a result, there is a need to develop ***interagency policies*** that will provide guidance to personnel involved in the coordinative interagency effort.

In addition, successful coordination requires the development of a new ***interagency structure*** that is used by the participating agencies to administer the interorganizational arrangement. It often takes the form of a specially appointed interagency committee whose members represent the needs of their individual agencies as they develop and monitor the interagency effort. In addition, staff are often assigned directly to the new unit to carry out the interagency objective. As was the case with cooperation, primary loyalty and responsibility of staff is to the single agencies rather than the interagency effort.

Once the interagency objective is accomplished through the coordinative effort, the interagency structure is no longer needed and is usually dissolved. In addressing the problem of reducing the number of high school drop-outs, the agencies in our example would need to appoint an interagency

committee to oversee the interagency effort. They would also have to modify their individual outreach activities to the targeted population. Unlike cooperative efforts, both the development of interagency policy and the creation of an interagency structure are demonstrations of the degree of formality that individual agencies attach to a coordinative interagency effort.

Because coordination usually requires a larger ***resource*** commitment than cooperative interagency efforts, single agencies need to dedicate funds from their separate agency budgets to the interorganizational effort. These resources remain within the control of the individual agencies. Participating agencies generally provide resources to support those aspects of the effort for which they are individually responsible and also usually bear some of the costs relative to maintaining coordination. Agency personnel working on the coordinated activity are ordinarily empowered to support those decisions made within the framework of the coordinated activity as long as they do not exceed existing budgetary and policy limitations. The amount of resources that each agency contributes to the coordinative interagency effort is reassessed annually, primarily on the basis of single agency needs and concerns.

Coordinated interagency efforts require some ***loyalty*** of the participating agencies ***to the interagency effort***; however, primary loyalty, as was the case with cooperation, rests with the individual agencies. Participating units become involved in the coordinative interagency arrangement and agree to the need to have their personnel work in tandem because accomplishment of the interagency objective results in improved individual agency performance.

Disagreements about areas of responsibility typically arise in coordinative interagency efforts; therefore, procedures to ***establish agreement*** about territorial issues need to be developed. Successful coordinative arrangements use "majority rule" voting processes to resolve these kinds of conflicts. In the coordinative effort to reduce the number of high school drop-outs, it is likely that participating agencies will attempt to assign financial responsibility for overlapping services to their partner agencies. Procedures need to be established to obtain agreement about how to resolve conflicts about this recurring problem. These issues can be successfully resolved using "majority rule" voting procedures to obtain agreement.

Representatives of participating agencies in the coordinative interagency activity must engage in extensive information sharing with regard to the specific objective that is sought; that is, each agency must make certain that its efforts do not interfere with those of other participating agencies. Also, each agency must be supportive of the activities of the other agencies. Information sharing about these issues begins with the members of the coordinating committee (i.e., the interagency structure developed to monitor the coordinative interorganizational relationship). Moreover, such

information sharing facilitates the development of effective decision making processes in the coordinative interagency effort.

For example, the overall objective of reducing the number of high school drop-outs is not easily defined and assessed. Each of the participating agencies is already working with these clients independently. They will need to share considerable information about what they wish to continue to do independently and about what they will pursue in the coordinative interagency arrangement. Agencies will need to vote to decide which collective activities will be pursued. When these agreements are reached, activities designed to coordinate services for prevention of an increase in high school drop-outs can be undertaken.

Decisions to participate in a coordinated effort are usually made through routine organizational processes. Once the decision is made, agencies will need to create interagency decision processes that facilitate resolution of issues related to the collective activities, including which personnel will be involved, what decision making latitude will be granted, and how resources will be used. ***Interagency decision making*** in coordinative interagency efforts is a much more critical issue than it is in cooperative arrangements. In successful coordinated interagency activities, interagency decisions must remain consistent with single agency decisions; as is the case with cooperation, the needs of the interagency effort are considered secondary to the needs of the individual agencies.

The ***roles of personnel*** assigned to the coordinating committee are more complex than they were in cooperative interagency efforts. Interagency policy issues are decided by personnel whose primary function is to represent their individual agencies' interests in the coordinative arrangement. At the same time, these individuals often become invested in seeing that the interagency objective is accomplished. Therefore, they find themselves in the position of also having to represent the concerns of the interagency effort to their home organizations. Often, these two roles are not compatible. It is not unusual to find single agency representatives on an interagency committee to reduce the number of high school drop-outs, for example, serving as advocates of the interagency activity and seeking additional contributions from their home agencies for the coordinated interagency effort. Finally, staff may be assigned directly to the interagency effort in order to carry out its coordinative activities.

In sum, within the framework of coordinated interagency relationships, creative efforts are usually directed toward implementation activities; therefore, procedures for working together on a continuing basis must be established. Coordination is a formal activity requiring time, resources and commitment by all participating agencies. It takes longer to accomplish than cooperation, but has the potential to provide more benefits to the individual agencies.

Table 2 below depicts the features of coordinated interagency efforts:

Table 2

Features of Coordinative Interagency Efforts

OBJECTIVE:	the interagency objective has a broad focus; it is intermediate-term or long-term
POLICY:	interagency policies are dictated by single agency policies
STRUCTURE:	requires the development of a new interagency unit; also, staff may be assigned directly to the new unit
RESOURCES:	supported with dedicated funds from the individual agencies which remain within the control of the individual agencies
LOYALTY:	primary loyalty is to the individual agencies; secondary loyalty is to the interagency effort
AGREEMENTS:	disagreements about territorial issues are resolved through "majority rule" voting processes
DECISION MAKING:	interagency decisions are consistent with single gency decisions; single agency needs are primary; the needs of the interagency effort are secondary
PERSONNEL ROLES:	policy issues are decided by committee members whose primary function is to represent their individual agencies' interests, but who also demonstrate a commitment to the interagency objective

Collaboration

Collaborative interagency arrangements require extensive interdependence among individual agencies. They occur only when two or more single agencies go beyond short-term or intermediate interests and focus instead on the requirements for accomplishing specified objectives which, when met, will also satisfy long-term interests of the participating organizations and units. Therefore, they take much longer to develop than either cooperative or coordinative interagency efforts. Once established, however, collaborative interagency relationships have the potential to provide much more extensive benefits to participating organizations. In effect, collaboration requires that agencies engage in fundamental alterations which affect policy,

structure, decision making, personnel roles and authority or control. Thus, collaborative interagency efforts are usually engaged in only when the issues under consideration are so complex or so costly that neither cooperation or coordination will suffice.

Interagency objectives appropriate for collaboration are broad in focus and require extensive commitment of the agencies involved. Collaborative interagency efforts are directed toward the attainment of objectives which can not be met by individual organizations, either because their mandates preclude such activities or because there is no possible way that the needed resources could be made available even if massive reallocation were considered. Such interagency objectives may begin as clearly definable and assessable, but are more commonly obtuse and intuitively assessed; further, there is a tendency for the objective to shift over time.

An example of collaboration might occur when, for the sake of conjecture, three agencies that individually focus on education, youth and adolescents, and health decide for some reason that there is an overwhelming need to direct their services to support families in crisis. The State, for whatever reasons, has directed the single agencies to accomplish this objective using an interagency approach. Agencies must devote considerable attention to establishing an appropriate interagency arrangement to accommodate this broad interagency goal. The one fact which is certain is that no single agency has the requisite resources or skills required to accomplish the objective independently. This task will require support from the individual agencies which will reflect positively on each sometime in the future when the effects of this effort become evident; however, in the short-term the effort is likely to be a constant drain on agencies' resources. In effect, collaboration is the appropriate interagency effort to accomplish this collective objective.

Collaboration always requires some modification of existing agency policies, as well as the creation of new ***interagency policies*** that support the interorganizational arrangement. In the example of agencies collaborating to support families in crisis, participants will need to create new interagency policies that will provide guidance as this complex objective is pursued. In addition, an interagency policy is needed to authorize the new collaborative unit to pursue the interagency objective autonomously.

As is the case with coordination, collaborative interagency efforts always require the development of a new ***interagency structure***. Over time, the new unit supplants individual agency authority to accomplish the interagency objective. Staff are assigned directly to the new unit and the collaborative effort becomes their primary responsibility. Typically, single agency interests are represented through a policy board that oversees the collaborative enterprise. However, responsibility for all operations rests with the collaborative unit, and not with the individual agencies. In effect.

the new unit is given authority to make decisions about planning and operation of the collaborative interagency effort. Such a unit would be needed in the interagency effort to support families in crisis.

Collaborative interagency relationships are supported with pooled ***resources*** which are largely within the control of the collaborative unit. Participating agencies are expected to provide resources to the new unit in order to support the commonly accepted mission of the collaborative; often, agencies make substantial yearly contributions to the collaborative unit in exchange for ongoing participation in its activities. In addition, collaborative interorganizational arrangements often seek out additional resources by applying for grants or by generating their own sources of income.

Unlike cooperation and coordination, primary ***loyalty*** is ***to the interagency effort*** rather than to the concerns of individual agencies. Such loyalty is possible because collaborative interagency arrangements are based upon, and require the building and maintenance of trust relationships among agency participants and between the new collaborative unit and each member agency. Personnel assigned to work for the collaborative enterprise obtain their power to act and make decisions from the collaborative itself through the policy board rather than from the individual agencies.

In order for collaboration to work, the collaborative unit must engage in a series of planning activities designed to ensure that the individual agencies receive an equitable share of the benefits and resources. That is. agencies must believe that they are receiving a fair share of the benefits in exchange for their investment in the collaborative effort. A key factor in the development of such trust is the creation of interagency procedures for ***establishing agreement*** about what are legitimate concerns of the new collaborative unit and what issues will remain the prerogatives of the single agencies. Unlike coordination where "majority rule" voting processes will suffice, collaborative interagency efforts require procedures that resolve disagreements about territorial issues through consensus building. All involved agencies must agree about these critical issues.

In large part, such shared ***decision making processes*** distinguish collaborative interagency efforts from cooperation and coordination. Without them, collaboration is not possible. Moreover, within collaborative interagency arrangements, decisions are commonly made on the basis of how best to achieve the interagency objectives. Decision making processes that work in collaborative interagency arrangements require extensive information sharing among the individuals involved in the collaborative effort, within single agencies, among participating agencies, and between single agencies and the collaborative. This information sharing commonly goes beyond the needs of the interagency objective and encompasses a wide range of peripheral issues. In effect, collaborative relationships require a high degree of risk-taking on the part of individual agencies that agree to entrust the collaborative with

responsibility to accomplish its interagency objectives in the best way without continuous reference to the individual agencies for direction or approval. Typically, this autonomy to develop and implement policy results in a state of tension between the collaborative unit and the individual agencies.

The *role of personnel* in collaborative interagency efforts differs in some aspects from the roles played by individuals in cooperative and coordinative interorganizational arrangements. Collaborative efforts are carried out by staff whose primary responsibility and loyalty is to the new collaborative unit rather than to the individual agencies. Those who work in the collaborative tend to become a close-knit work unit willing to share all necessary information among themselves; this information sharing often exceeds the direct requirements of the task and occasionally results in decisions which conflict with the short term interests of the individual agencies. In addition, new collaborative units must have sufficient staff to accomplish their objectives. They also require as directors persons who are comfortable with exercising leadership in a highly political, ambiguous environment where the need to provide vision to the enterprise is as important as the ability to administer daily operations.

In addition to staff, collaborative units have policy boards that are primarily composed of representatives of participating single agencies. These individuals have a dual responsibility which has the potential to create role conflict. First, they have the responsibility to oversee the interagency effort in order to ensure that interorganizational activities are successful. At the same time, they are employees of their home organizations and are expected to protect their own organizations' interests. In successful collaborative interagency efforts, policy board members become advocates of interagency objectives in their home organizations and actively involve other appropriate persons and units in the accomplishment of the collaborative's activities. The more informed and involved single member agencies are, the more likely that the collaborative unit will be able to implement its interagency objectives successfully.

Our example of a collaborative interagency effort to support families in crisis cannot be accomplished unless all of these personnel issues are addressed. The collaborative unit must have its own staff, and policy board members must fulfill multiple responsibilities if the interagency objective is to be accomplished.

In sum, collaborative interagency efforts represent a higher degree of interdependence than coordinative and cooperative arrangements. The creative efforts of the collaborative will initially be directed toward defining the nature of the problem to be addressed, toward creating appropriate inter-organizational procedures, toward establishing an effective work group in the new collaborative unit, and after that toward developing means for accomplishing the objectives. The development of an effective policy board is

also a key factor in successful collaborative units. Table 3 below depicts the features of collaborative interagency efforts:

Table 3

Features of Collaborative Interagency Efforts

OBJECTIVE:	the interagency objective has a broad focus and is long-term
POLICY:	interagency policies are determined by the collaborative unit
STRUCTURE:	requires the development and maintenance of a new interagency unit that functions relatively autonomously; staff must be assigned directly to the new unit
RESOURCES:	supported with pooled resources which are largely within the control of the collaborative unit
LOYALTY:	primary loyalty is to the interagency effort; secondary loyalty is to the individual agencies
AGREEMENT:	disagreements about territorial issues are resolved through consensus building
DECISION MAKING:	interagency decisions are made by the collaborative unit; interagency needs are primary; single agency needs are secondary
PERSONNEL ROLES:	carried out by personnel whose primary responsibility is to accomplish the interagency objective; committee members actively protect interagency needs and concerns in their home organizations

The Three Types of Interagency Efforts

Cooperation, coordination and collaboration are all appropriate interagency approaches to accomplishing different kinds of interorganizational objectives. The broader and more complex the interagency objective, the more agency interdependence required. The need to develop interagency policies and new interagency structures expands as the degree of agency interdependence increases. Cooperation and coordination are dependent on single agency resource contributions; collaboration requires pooled agency resources.

The greater the degree of interdependence, the greater the need for agency representatives to shift their primary loyalty from single agency concerns to the interagency effort, and the more likely that procedures will need to be developed to resolve disagreements about territorial issues. Coordinative interagency efforts can be accomplished successfully using "majority rule" voting procedures for conflict resolution; collaboration requires the building of consensus in establishing agreement. All participating agencies must agree on what are legitimate interagency concerns and what are appropriate single agency responsibilities.

In cooperation and coordination, interagency decisions are made primarily by single agencies; primary authority for decision making in collaborative interagency efforts is assigned to the collaborative unit. Staff and committee members play critical roles in ensuring that a particular interagency effort works. The greater the degree of interdependence, the more need for personnel who have full time responsibility to the interagency unit, who are risk-takers, and who have the capacity to address complex interagency problems creatively. Issues related to possible role conflicts must be addressed. In collaborative interagency efforts, committee members play critical roles in balancing interagency needs with the concerns of single agency participants. The greater the degree of interdependence, the more need for committee members to represent the concerns of the interagency effort in their home organizations.

Bottom line, each type of interagency effort is potentially effective. Decisions about which type to use begin with an analysis of the interagency objective(s) to be accomplished. Organizational conditions, interagency procedures and interpersonal relationships then need to be deliberately structured to fit the nature of the interagency objective. Coordination and collaboration can not be implemented solely by signing an interagency agreement or contract. Energies need to be systematically devoted to addressing the issues described above.

A comparison of these three interagency types is portrayed in Table 4 on the next page.

Table 4

Types of Interagency Efforts

Features	COOPERATION	COORDINATION	COLLABORATION
OBJECTIVE	narrow focus; short-term	broad focus; short or intermediate term	broad focus; long-term
POLICY	no interagency policies required	interagency policies are dictated by single agency policies	interagency policies are determined by the collaborative unit
STRUCTURE	no new interagency structure is required; agency personnel are assigned to achieve the objective	requires development of a new interagency unit; staff may be directly assigned to the new unit	requires development and maintenance of new unit; staff must be assigned directly to the new interagency unit
RESOURCES	supported with discretionary funds which remain within the control of the individual agencies	supported with dedicated funds from the individual agencies that remain within the control of individual agencies	supported by pooled resources that are largely within the control of the collaborative interagency unit
LOYALTY	no loyalty to the interagency effort is required; loyalty is to the individual agencies	primary loyalty is to the individual agencies; secondary loyalty is to the interagency effort	primary loyalty is to the interagency effort; secondary loyalty is to the individual agencies
AGREEMENT	no major single agency territorial issues arise; agreement is not an issue	disagreements about territorial issues are resolved through "majority rule" voting procedures	disagreements about territorial issues are resolved through the development of consensus
DECISION MAKING	interagency decisions are made by the single agencies; interagency needs are secondary to agency needs	interagency decisions are consistent with single agency decisions; interagency needs are secondary to single agency needs	interagency decisions are made by the collaborative unit; single agency needs secondary to interagency needs
PERSONNEL ROLES	carried out by personnel whose primary function is to represent their individual agencies' interests and who are assigned responsibility for the interagency effort on a short term basis	policy issues are decided by interagency committee members whose primary function is to represent their individual agencies' interests, but who also demonstrate commitment to the interagency objective	carried out by personnel whose primary responsibility is to accomplish the interagency objective; committee members actively protect interagency needs and concerns in their home agencies

REFERENCES

Executive Order 01.01.1988.15, [State's] Infants And Toddlers Program, October 25, 1988

Gittler, Josephine. Community-Based Service Systems For Children With Special Health Care Needs And Their Families. Iowa City, IA; National Maternal And Child Health Resource Center, 1988.

FOR INFORMATION CONTACT:

National Maternal And Child Health Resource Center
College of Law Building
The University of Iowa
Iowa City, IA 52242
(319) 335-90677

Goldman, Harvey and Intriligator, Barbara. A Profile of State Interagency Efforts For Children With Special Needs And Their Families. Arlington, VA; ICA Corporation, July 1988.

FOR INFORMATION CONTACT:

ICA
4212 South 32nd Street
Arlington, VA 22206
(703) 931-6809

P.L. 99-457, The Education of The Handicapped Amendments of 1986, October 1986.

Serving Children With Special Needs; [State's] Evolving System. Report prepared by the Department of Health and Mental Hygiene, the Department of Human Resources, the Juvenile Services Agency and the State Department of Education, April 29, 1988.